Socio-cultural and Health Care Contexts of Perinatal Survival in Rural Mountain Villages of Nepal

by

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DECLARATION

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Signed..

Date: 11/05/2018

ABSTRACT

Worldwide, over 14,500 perinatal deaths occur daily, with a majority happening in Sub Saharan Africa and South Asia. Nepal has high perinatal mortality with its mountainous areas showing the highest rates. Nationally, only about half of the women utilise skilled care during pregnancy, childbirth and postnatal periods, and fewer still in the mountainous areas. The focus of research and policy to improve perinatal survival has so far remained on their medical determinants. The present study aims to examine socio-cultural factors influencing perinatal survival in two remote Nepalese mountain villages. The specific objectives of the thesis are to: 1) explore women's and their family members' experience and beliefs about perinatal sickness and deaths; 2) examine the socio-cultural context of experiencing pregnancy, childbirth and perinatal deaths; 3) examine the health care delivery contexts of perinatal survival at primary health care levels; and 4) consider the implications for health policy development and implementation in the villages.

This is a qualitative study, informed by social constructionist and critical theoretical perspectives and based on in-depth interviews of women and family members experiencing perinatal deaths in the selected villages. Interview data were supplemented by reviews of policy documents and interviews of frontline health workers and others. Data were analysed using inductive thematic analysis with comprehensive coding processes. Three key themes and sub-themes emerged from the data:

1. *Fatalistic beliefs concerning acceptance of perinatal sickness and deaths*. Sub-themes: i) 'everyone has gone through it': perinatal death as a natural occurrence; ii) The will of *Dewata* (God*)* as a factor in health and sickness: a cause of, and means to overcome sickness in mother and baby; iii) *Karma (past deeds)*, *Bhagya* (fate*)* or *Lekhanta* (destiny) - ways of rationalising perinatal deaths.
2. *Gendered social constructs of motherhood and poor perinatal survival.* Sub-themes: i) gendered social construct and vulnerability to poor perinatal survival: child marriages, son preference and repeated childbearing; ii) pregnancy and childbirth in intra-familial dynamics of relationships and power; iii) perception of childbirth as a polluted event: birth in *Gotha* (cowshed*)*, giving birth alone.
3. *Declining essence of primary health care and health governance failures*. Sub-themes: i) Approach of health care delivery: low focus on empowerment and engagement; ii) quality of health care: poor acceptance, feeling unsafe and uncomfortable in health facilities; iii) health governance failures in delivering pregnancy and childbirth services.

The findings reveal the insufficiency of medically oriented health services for reducing this region's continuing high perinatal mortality. Addressing the social and cultural determinants of perinatal mortality is paramount for its prevention. This study makes a case for perinatal survival drawing on lay perspectives gained from the women and their families, allowing effective exploration of factors influencing perinatal survival within their socio-cultural and health service contexts. It shows how to consider socio-cultural factors including gender, power structure and social norms for developing appropriate policies and programs for improving perinatal survival. It calls for urgent attention to develop policies and services culturally and socially appropriate to enable women access to safer perinatal outcomes.

ACKNOWLEDGEMENTS

PREFACE

I was born in a poor village family in the country side of western Nepal. I grew up with five siblings and was raised by my father. I started schooling living in my elder sister's house. After her marriage at the age of 14, I gave company to her as most of the time she had to stay alone and take care of a buffalo, a pair of goats and a few hens, and had to do cropping and harvesting on her own. My brother-in-law worked as a domestic help in India, who provided the only means of subsistence for the family. Living in my sister's house was the best choice that my father could offer after my mother's death in her early 40s. When my mother died, I was just 4 years old, and had a younger brother who was still a toddler. Growing up, my father explained to me that my mother had suffered from postpartum haemorrhage and lower abdominal pain after the birth of my youngest brother (the seventh child). Frequent spotting and pain did not stop and she died a year after giving birth to my brother.

I have witnessed death during my early childhood. Later, I also knew that my mother had lost her first child (my eldest brother) on the fourth day after birth. During my high school, I witnessed my younger sister losing her newborn baby. During that time, I did not know much about why that had happened, and I dared not ask my sister about this. But, this experience deeply touched me as I noticed that she was anxious about whether she would have a baby so that she would be well taken care of by her in-laws. I also saw similar anxiety with my father and my elder sister.

After high school, my father had a deep interest in seeing me as a medical doctor. I then enrolled in three years' proficiency level general medicine course. After completing this, I began my career as a Health Assistant (medical assistant), working in a rural village of Nepal's far-western region, one of the most underdeveloped regions of the country. Working at a village level health facility, with health volunteers and community groups, I grew up with an interest to pursue higher education in public health. I continued my study in a Bachelor's Degree in Public Health from Tribhuvan University of Nepal. After graduating in public health in 2005, I started working as a training facilitator for community-based integrated management of childhood illness in mountain villages of the *Karnali* region, the most disadvantaged region of Nepal. As a facilitator, I had the opportunity to learn from the experience of a range of primary health care workers and health volunteers who had been working for years in the remote and rural villages in the mountains. I heard several stories of infant and child deaths during these training sessions, and during repeated trips into the villages. These stories upset me greatly. The more I spent in the villages conducting training in the regions, the more I found myself lacking knowledge about the local contexts of the villages in which mothers and babies continued to become sick and die. If I could recollect those experiences now, I would call myself as someone who was spoon-fed or swallowed information merely on medical aspects of child deaths, largely about danger signs (during pregnancy, childbirth, postnatal). I was pushing health workers and health volunteers to memorise these

danger signs. The contexts were different from what I as a trainer was giving, a kind of tailored type medical prescription to prevent infections and infant deaths. After these field experiences, I became more passionate to continue to work on mother and infant health care and survival.

Later, I joined UNICEF Nepal to work for its maternal and newborn health project. I was based in a remote and rural far-western hilly district. Strengthening birthing sites in the villages, facilitating community groups and stakeholders to ensure quality care for mother and baby were the key aspects of the project in which I was involved. I witnessed women suffering from retained placenta for over a week and coming to hospital with a foul odour. I saw several women giving birth in their cowshed and losing their newborns. I also witnessed the weaknesses and inefficiencies at district and village health facilities, thus further engendering the vulnerabilities of women losing their own lives and that of their newborns/infants. Such experience and exposure made me frustrated and angered with the system, and I had moments of low motivation with ongoing tailored type technical training related to saving mothers and newborn babies in the district.

Having seen at first hand the experiences of women and families' lives and livelihood in mountain villages, I had a deep interest to bring out what they were going through in their struggle to save their own lives and that of their babies. In this thesis, I have attempted to explore their experiences which I hope would be insightful to current policies and practices if we are to stop persistent baby losses by these women who are poor, disadvantaged and isolated in the mountains of Nepal. Having seen the tragedies within my family and kinship, and that of the poor women and families in Nepal's remote and rural hilly and mountainous region, I have due respect for the voices of women and families and health service providers from the disadvantaged villages. I hope their stories will be the means of motivation to guide everyone, and the means to add their voice to help reach every family to cherish a healthy pregnancy and healthy newborn child.

THESIS OUTPUTS

Conference Proceedings/Media Release

1. Mohan Paudel, Sara Javanparast, Gour Dasvarma. *Delivery of health care for perinatal survival in mountainous villages of Nepal: Understanding the health care context at the local level.* Australian Society for Medical Research (ASMR), Medical Research Week, South Australian Scientific Meeting. The Adelaide Convention Centre, June 8th 2016 (Page 136 of the ASMR 2016 SA Scientific Meeting Report)

2. Mohan Paudel, Sara Javanparast, Gour Dasvarma. *Critical Account on Policy Context of Perinatal Survival in Nepal.* The 2nd International Conference on Public Health (ICOPH 2016) 28th to 29th of July, 2016, Colombo, Sri Lanka (Page 184 of the conference abstract book)

3. Mohan Paudel, Sara Javanparast, Gour Dasvarma. *Perceptions about sickness and causes of perinatal deaths in remote mountainous villages of Nepal.* 2016 State Population Health Conference, Reaching for the sky: building the links between research and practice, Hindmarsh, Adelaide, South Australia, 22 October 2016 (Page 2, Program-at-a-Glance)

4. Mohan Paudel, Sara Javanparast, Gour Dasvarma. *Motherhood experiences and perinatal survival in mountainous villages of Nepal.* The 21st ICOWHI Congress *Scale and Sustainability: Moving Women's Health Forward*, November 6 to 9, 2016**,** Baltimore, Maryland, USA. (Page 1, Congress Schedule)

5. Mohan Paudel, Sara Javanparast, Gour Dasvarma. *Perceptions about Perinatal Deaths in the Mountainous Villages of Nepal: Fatalism and Acceptance Contributing to Poor Perinatal Survival.* 4th World Congress on Integrated Care, 23-25 November 2016, Wellington, New Zealsnd (Accepted)

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7. Flinders University (2018), Nepal battles high child mortality. Scimex, Breaking Science News for Australia and New Zealand. URL: https://www.scimex.org/newsfeed/nepal-battles-high-child-mortality

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1. Paudel M, Javanparast S, Dasvarma G, Newman L (2018) Religio-cultural factors contributing to perinatal mortality and morbidity in mountain villages of Nepal: Implications for future healthcare provision. PLoS ONE 13(3): e0194328. https://doi.org/10.1371/journal.pone.0194328

2. Paudel., M., Javanparast, S., Dasvarma, G., & Newman, L. (2018). A qualitative study about the gendered experiences of motherhood and perinatal mortality in mountain villages of Nepal: implications for improving perinatal survival. BMC pregnancy and childbirth, 18(1), 163. doi: 10.1186/s12884-018-1776-3

3. Paudel M, Javanparast S, Dasvarma G, Newman L (2018) A Critical Account of the Policy Context Shaping Perinatal Survival in Nepal: Policy Tension of Socio-Cultural Versus a Medical Approach. BMC Health Services Research [Under Review]

4. Paudel M, Javanparast S, Dasvarma G, Newman L (2018) Health System Barriers Influencing Perinatal Survival in Mountain Villages of Nepal: Implications for Future Policies and Practices. Journal of Health, Population and Nutrition [Under Review]

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LIST OF ACRONYMS

AHW	Auxiliary Health Worker
ANC	Antenatal Care
ANM	Auxiliary Nurse Midwife
ARI	Acute Respiratory Infection
AUD	Australian Dollar
BCC	Behaviour Change Communication
BEmONC	Basic Emergency Obstetric and Newborn Care
CAC	Comprehensive Abortion Care
CBAC	Community Based Acute Respiratory Infection Control
CB-IMCI	Community Based Integrated Management of Childhood Illness
CB-IMNCI	Community Based Integrated Management of Neonatal and Childhood Illness
CB-NCP	Community Based Newborn Care Programme
CBS	Central Bureau of Statistics
CDD	Control of Diarrhoeal Diseases
CEmONC	Comprehensive Emergency Obstetric and Newborn Care
CHD	Child Health Division
CHW	Community Health Worker
CoIA	Commission on Information and Accountability
CS	Caesarean Section
CSDH	Commission on Social Determinants of Health
DDA	Department of Drug Administration
DDC	District Development Committee
DFID	Department For International Development (UK)
DHMC	District Health Management Committee
DHO	District Health Office
DOA	Department of Ayurveda
DoHS	Department of Health Services
ENAP	Every Newborn Action Plan
EWEN	Every Women Every Newborn
FAO	Food and Agricultural Organisation
FCHV	Female Community Health Volunteers
FHD	Family Health Division
FP	Family Planning
GDI	Gross Domestic Index
GII	Gender Inequality Index
HA	Health Assistant
HDI	Human Development Index
HERD	Health Education, Research and Development
HFOMC	Health Facility Operation and Management Committee
HIV/TB	Human Immuno Deficiency Virus/Tuberculosis
HMIS	Health Management Information System
HP	Health Post
I/NGOs	International/Non-Governmental Organisation
ICPD	International Conference on Population and Development
IMCI	Integrated Management of Childhood Illness

IRIN	Integrated Regional Information Networks
IUGR	Intra Uterine Growth Retardation
KMC	Kangaroo Mother Care
LBW	Low Birth Weight
LSTM	Liverpool School of Tropical Medicine
MCH	Maternal and Child Health
MCHW	Maternal and Child Health Worker
MDG	Millennium Development Goal
MDR	Maternal Death Review
MG	Mothers' Group
MNH	Maternal and Newborn Health
MNHG	Maternal and Neonatal Health Group
MOHP	Ministry of Health and Population
MPDR	Maternal and Perinatal Death Review
MPDSR	Maternal and Perinatal Death Surveillance and Response
NDHS	Nepal Demographic and Health Survey
NHMRC	National Health and Medical Research Council
NHRC	Nepal Health Research Council
NICU	Neonatal Intensive Care Unit
NMR	Neonatal Mortality Rate
NPC	National Planning Commission
NRs	Nepalese Rupees
NSMNLTP	National Safe Motherhood and Newborn Health Long Term Plan
NSMLTP	National Safe Motherhood Long Term Plan
NSMP	Nepal Safe Motherhood Project
ORC	Out Reach Clinic
PDR	Perinatal Death Review
PDSA	Perinatal Death Surveillance and Assessment
PHC	Primary Health Care
PHCC	Primary Health Care Centre
PHC-ORC	Primary Health Care Out Reach Clinic
PMR	Perinatal Mortality Rate
RHCC	Reproductive Health Coordination Committee
RMNCH	Reproductive, Maternal, Newborn and Child Health
SBA	Skilled Birth Attendant
SBREC	Social and Behavioural Research Ethics Committee
SDG	Social Development Goal
SDH	Social Determinants of Health
SDIP	Safe Delivery Incentive Programme
SDK	Safe Delivery Kit
SHP	Sub Health Post
SMNH	Safe Motherhood and Newborn Health
SN	Staff Nurse
SSMP	Support to Safe Motherhood Programme
TBA	Traditional Birth Attendant
TT	Tetanus Toxoid
UMN	United Mission to Nepal
UN	United Nations
UNDP	United Nations Development Programme

UNFPA	United Nations Population Fund
UNICEF	United Nations Children's Fund
USG	Ultrasonography
VDC	Village Development Committee
VHW	Village Health Worker
WFP	World Food Programme
WHO	World Health Organisation

INTRODUCTION

Pregnancy and childbirth are special events in a woman's life. In many settings, the provision of physical, emotional and social support to make these events healthy and joyful has been influenced by the prevailing social and cultural practices and existing health policies and programmes. Pregnancy and childbirth in turn have attracted the attention of health planners, policymakers and researchers for many decades. The just concluded United Nations program on Millennium Development Goals (MDGs) 2000-2015 (World Health Organization [WHO], 2015a) has greatly sensitised governments to reducing maternal and child mortality rates. At the same time, the gaps in quality, equity and coverage in health care between and within countries have become even more vivid, leaving a lot to be done from the beginning of the new era of the United Nations Sustainable Development Goals (SDGs) 2015-2030 (Every Woman Every Child, 2015; United Nations Childrens' Fund [UNICEF], 2015a; WHO, 2015a).

Inequity in pregnancy outcomes and complications is a global concern. Public health and bio-medical evidence about the causes, consequences and the whereabouts of maternal, perinatal and child mortalities are becoming clearer. While developed countries are experiencing the lowest rates of maternal, perinatal and child mortalities, less developed regions are still suffering from issues in relation to health care provision, social support and poor economic conditions (WHO, 2014c). Regarding perinatal mortality, more than 600 stillbirths and newborn deaths continue to occur every hour worldwide (WHO, 2017a, 2017c), and almost all of them are from developing countries, with rural areas suffering the most. Three-quarters of all child deaths including newborn deaths (UNICEF, 2015b), and more than three-quarters of stillbirths occur in Sub Saharan Africa and South Asian countries (Blencowe et al., 2016). Even within these countries, the most affected are the rural, poor, disadvantaged and indigenous populations. Although national rates are declining, the inequity at sub-national levels is prominent in many developing countries. In Nepal, although the national under-five, infant and neonatal mortality rates[1] are 54, 46 and 33 per 1,000 livebirths respectively, in the mountainous regions the same rates are 87, 73 and 46 per 1,000 livebirths respectively (Ministry of Health and Population [MOHP], New ERA, & ICF International Inc., 2012), equivalent to the highest in the world. Counting of stillbirths has not yet become a priority in Nepal or its mountainous region and therefore it often remains neglected. Besides

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[1] The latest rates available as this study commenced, as per Nepal Demographic and Health Survey Report published in 2012

geographical variations in mortality, Nepal has one of the largest inequities in neonatal mortality by economic status. According to 2012 neonatal mortality data, Nepal would be ranked second to Cambodia in terms of the size of relative neonatal mortality reduction if the equity gap between rich and poor was closed (Lawn et al., 2014). It is estimated that in Nepal, if the poorest 20% had a risk of neonatal deaths similar to that of the richest 20%, then the national neonatal mortality rate would be reduced by 46% from its 2012 level (Lawn et al., 2014).

Given the current progress, it is estimated that it will take approximately one hundred years for a developing country to reach the mortality level (neonatal mortality and stillbirths) currently experienced by a developed country (Lawn et al., 2014; Lawn et al., 2016).

Pregnancy and childbirth should be celebrated with joy and happiness (WHO, 2005, 2014c), but this is not the case for the majority of women in Nepal. Pregnant women and their newborn babies are most vulnerable to sickness and death. The situation of pregnancy, childbirth and newborn health is particularly challenging in the mountainous regions of Nepal. Hundreds of mothers and babies lose their lives every year during pregnancy, childbirth and early infancy, yet little has been done to remedy the situation. Although policies and programmes have been in place for decades aiming to save mothers and children's lives, there has been little success in tackling the problem in the mountainous regions. This poses a critical question to explore the root causes of high prevalence of childhood mortality in these regions. Is it only the remoteness of the region, or are there other factors at play? Needless to say, all efforts must be made to help protect the lives of these women and their newborn babies.

Globally, a great deal of evidence is available on the medical and epidemiological aspects of perinatal mortality (stillbirths and early-neonatal deaths) that have provided the foundation for the development of policies and programmes to address the prevailing high perinatal mortality in developing countries. Thus, up until now, the bio-medical approach remains the predominant strategy in preventing perinatal deaths, which primarily emphasises the health seeking behaviour and medical care to treat the sicknesses and obstetric complications among mothers and babies (Bhutta et al., 2014; Lawn et al., 2014). The main focus of preventing neonatal deaths has remained on treatment of infections and managing asphyxia and complications related to prematurity.

The bio-medical/epidemiological approach has been crucial in achieving global declines in perinatal deaths. It is acknowledged that providing medical care during complications of the mother and child is undeniable (WHO, 2014c). Despite this fact, we witness an ongoing disparity across and within countries that requires both researchers and policy makers to look at the root causes of the problems such as socio-cultural contexts. Perinatal death rates are declining in many parts of the world, but in many developing countries, such as in Nepal, as discussed above, the progress is

not even. There is a knowledge gap on the socio-cultural aspects that influence women's and their families' practices in pregnancy, childbirth and postnatal care, and their experience of health programmes and interventions (Kaphle, Hancock, & Newman, 2013). Available studies are limited in scope in describing a pattern of mortality or health care utilisation (Paudel, Shrestha, Siebeck, & Rehfuess, 2013a; Paudel, Thapa, Shedain, & Paudel, 2013b) and in identifying medical causes of neonatal deaths (Dhakwa et al., 2014; Khanal et al., 2011b; Manandhar et al., 2015; Manandhar et al., 2010; Shrestha, Manandhar, Dhakal, & Nepal, 2006).

In accelerating the reduction of perinatal mortality, studies now indicate the need to shift the focus from understanding the distribution i.e. what, where, when, and why of perinatal deaths focussing only on medical aspects towards an exploration of the influence of local socio-cultural contexts, and health system constraints in delivering health care and support to end preventable stillbirths and neonatal deaths (Dickson et al., 2015; Dickson et al., 2014).

The dilemma this thesis faces is how to reconcile the human losses with the socio-cultural challenges and still encourage the local people to use available resources and the medical evidence to ensure that the women and their babies survive. The main aim of this thesis is to investigate the experience of women, their families and frontline health workers with maternal and newborn care and perinatal deaths; and examine the socio-cultural and health care contexts of poor perinatal survival in the remote mountainous villages of Nepal.

The thesis is shaped by an overarching framework of social constructionism and a critical theoretical perspective applied to a public health issue. Use of these frameworks has underpinned the key methodological principles (experiences as source of knowledge, reflexivity in research, and data—the participants' experience and opinions about poor perinatal survival as naturally occurring events). Use of the guiding principles of both social constructionism and critical theoretical perspective has enabled me to explain the research findings (Chapter Two, Section 2.5.3). These theoretical perspectives have not only helped me to explore what women and families in the villages negotiate as their truth, they have also enabled me to examine the links between participants' descriptions and underlying forces shaping a poorer level of perinatal health experienced by them. ction 1.1 of this chapter provides definitions of key terms used in this thesis. Section 1.2 explains perinatal survival as a public health problem, Sections 1.3 and 1.4 draw on public health concepts, and concept of perinatal survival as outcomes of health systems functioning to support the focus of this thesis on socio-cultural factors and health systems. The subsequent sections describe the need for the research, research aims, research questions and objectives, and an overall outline of the thesis structure.

1.1 Definition of Key Terms

Perinatal period

The term 'perinatal' includes the time period both during pregnancy and after birth (WHO, 2000a). The concept of 'perinatal period' emerged in the late 1940s after clinicians and researchers noticed the large number of mortalities before and after birth (Peller, 1948). The most commonly used definition for the perinatal period comprises the time between 22 weeks of gestation to up to seven days after birth (WHO, 2000a). This definition is particularly used for international comparison of death rates between and within countries. However, a perinatal period extending from 20 weeks of gestation until the first 28 days after birth is also commonly in use, such as in Australia and in the United States (MacDorman & Gregory, 2015; Monk et al., 2016). This later definition is referred to as the extended perinatal period, and is considered useful for monitoring deaths throughout the gestational age spectrum (MacDorman & Gregory, 2015).

Stillbirth

Stillbirths refer to foetal deaths after 22 weeks of gestation until the birth. Babies dying during labour, (from onset of labour to before birth), are considered intra-partum stillbirths (Figure 1.1).

Newborn or neonatal death

Newborn or neonatal deaths comprise deaths of live-born babies after birth within the first 28 days of life. Deaths of live-born babies within the first seven days are called early neonatal deaths. The term newborn or neonatal death is also interchangeably used with early infant death. Infant deaths comprise deaths of live-born babies before the first 12 months of age. Deaths of live-born babies after the neonatal period (first 28 days) until the first 12 months of age are called post-neonatal deaths. Figure 1.1 illustrates definitions on child mortality measures used adapted from the Australian Institute of Health and Welfare.
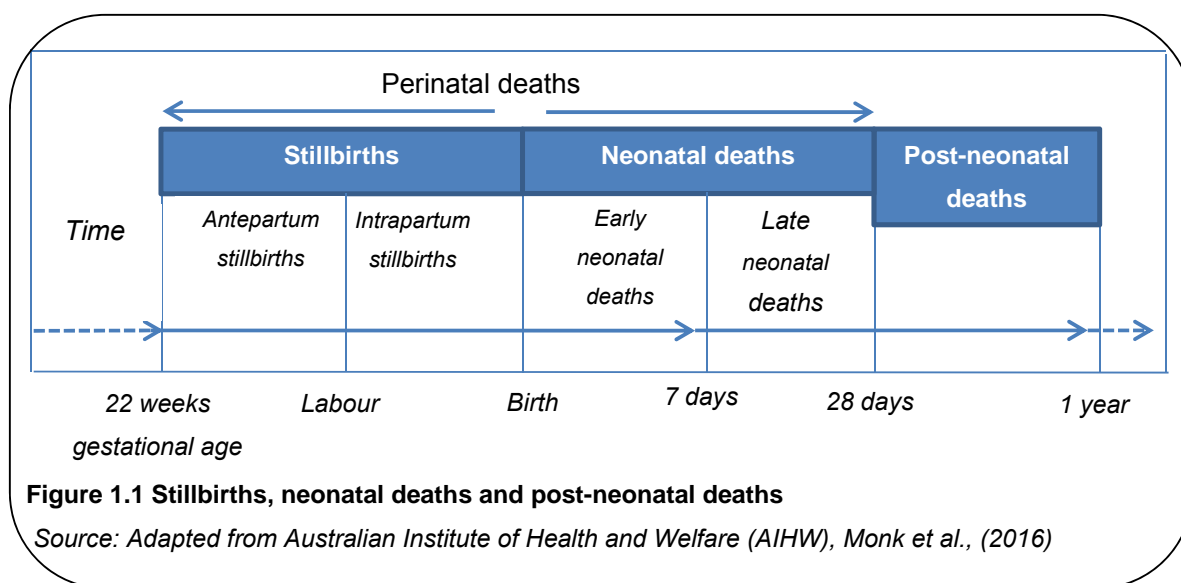
Figure 1.1 Stillbirths, neonatal deaths and post-neonatal deaths

Source: Adapted from Australian Institute of Health and Welfare (AIHW), Monk et al., (2016)

Until a few years ago, most developing countries were suffering from high mortality rates during infancy. Over the last few years, there has been a downward trend in post-neonatal and under-five mortality rates but the number of deaths in the perinatal period has remained high. This has led to growing attention to determinants of death during the perinatal period.

In this thesis, the perinatal period that comprises both stillbirths and neonatal deaths until the first 28 days after birth is used to examine socio-cultural and health care contexts contributing to care practice and utilisation. Unless otherwise specified, a perinatal death in this thesis refers to the deaths which occur during the extended perinatal period, thus including both stillbirths and neonatal deaths until the first 28 days after a livebirth. As this thesis is not bio-medical or epidemiological research, and the objective is to neither measure nor compare mortality estimates, this study has considered the deaths occurring during the extended perinatal period. Studies have frequently shown that stillbirths and neonatal deaths have similar aetiologies and that there are often similar interventions in a pregnancy and postnatal continuum that contribute the most to prevent stillbirths, neonatal and maternal deaths (Bhutta et al., 2014; Darmstadt et al., 2005; de Bernis et al., 2016).

1.2 Perinatal Mortality: A Public Health Problem Linked to Socio-Cultural Determinants

Rates, trend and distribution

Perinatal survival has been an ongoing public health priority. In 2015, the global rate of stillbirth was 19 per 1,000 births (Blencowe et al., 2016) and neonatal mortality rate was 21 per 1,000 livebirths (UNICEF, 2015b). Worldwide, more than 14,500 perinatal deaths are reported on a daily basis, comprising both stillbirths (WHO, 2017c) and neonatal deaths (WHO, 2017a). As for the situation in 2015 (WHO, 2017a), neonatal deaths comprise almost half (45%) of global under-five deaths. This proportion is even higher in some developing countries rising up to 60% of the total under-five deaths. Neonatal deaths comprise more than 75% of the infant deaths. Of the total neonatal deaths, more than two-thirds occur within the first week of life (early neonatal deaths).

Globally, studies show that the rates of reduction (between 2000 and 2015) of stillbirth rates (2%) and neonatal death rates (3.1%) are slower than post-neonatal under-five mortality rates (4.5%) (Lawn et al., 2016; You et al., 2015). This trend is even slower in Sub Saharan and South Asian countries.

Almost all (99%) perinatal deaths occur in developing countries, nearly two-thirds of them in Sub Saharan Africa and South Asia (Lawn et al., 2014; Lawn et al., 2016). Within these countries, the deaths and death rates are higher among the poor, disadvantaged and the rural population. It is also estimated that at the current pace of mortality reduction, it would take about 100 years for an

African and a South Asian woman to experience the same chance of saving her babies as a woman from a developed country (Lawn et al., 2014).

A Human right issue

Perinatal survival is a human rights issue. More than 25 years ago, the United Nations Convention on the Rights of the Child ratified child survival as a fundamental human right (UNICEF, 1989). According to Articles 6 and 24 of the convention, every newborn child has an inherent right to survival, development and highest attainable standard of health and access to care. Although discourse about right to life of a foetus remained silent, or a debated ethical question, the prevention of stillbirth has now been explicitly recognised by global policy such as the Every Newborn Action Plan (WHO, 2014c). This policy has begun to humanise stillbirths, and has integrated both the neonatal and stillbirth prevention as a global health policy agenda. However, there is still a long way to go to realise these rights, as we have not yet been able to stop every preventable child death, more so for stillbirths and neonatal deaths.

Socio-cultural factors

A variety of studies describe pregnancy and childbirth as a socio-cultural construct (Aziato, Ohemeng, & Omenyo, 2016; Callister & Khalaf, 2009; Crowther & Hall, 2015; Kaphle et al., 2013; Liamputtong, Yimyam, Parisunyakul, Baosoung, & Sansiriphun, 2005). These studies show that socio-cultural constructs continue to guide why people perceive, believe and behave the way they carry their beliefs, perceptions and practices during pregnancy, birth and the postnatal period. In the same way, perinatal survival is embedded in such constructions and influenced by socio-cultural factors. This involves individuals' perceptions and values about pregnancy, birth and related outcomes such as perinatal deaths. Kaphle et al. (2013) describe traditions, social values and culture shaping pregnancy and childbirth experiences, which have important bearings on women's choice and control that eventually affects the safety and survival of a mother and her baby. Other studies, however, describe stillbirths and neonatal deaths as non-human deaths, as things not worthy to share, as spiritual cleansing, and as of low concern, thus fostering a sense of fatalism about preventability of these deaths (Aggarwal, Kumar, & Kumar, 2003; Degefie, Amare, & Mulligan, 2014; Haws et al., 2010; Liamputtong, 2000).

Community-based interventions

A number of family and community-based strategies/interventions have been designed to tackle perinatal mortality that are based on the recognition of the importance of socio-cultural determinants in preventing perinatal deaths. Literature provides examples of successful interventions in reducing neonatal death rates and contributing to reducing stillbirth and maternal death rates (Bhutta et al., 2014; Lassi & Bhutta, 2015). Such interventions are proven to be more effective and appropriate in high mortality settings with a large number of homebirths demonstrating significant reductions in perinatal death rates, as evident in India (Bang, Reddy,

Deshmukh, Baitule, & Bang, 2005; Tripathy et al., 2010) and Bangladesh (Baqui et al., 2008). Similar interventions have been trialled with women's groups in Nepal (Manandhar et al., 2004), and community stakeholder groups in Vietnam (Persson et al., 2013). These interventions indicate the importance of socio-cultural factors as being critical in reducing perinatal mortality. Family and community-based interventions are generally aimed at improved survival of both mothers and their babies by increasing the engagement, awareness and empowerment of families and communities to promote healthy behaviour, to negotiate resources for maternal and newborn health, and to demand skilled care. Lack of community ownership, including unfavourable local socio-cultural aspects, and low community involvement, especially women's engagement have been identified as major bottlenecks in the success of interventions targeting newborn children for example treatment of neonatal infections, basic neonatal care, treatment of sick or premature and small sized newborns, and stillbirths prevention in developing countries (Dickson et al., 2015).

1.3 Perinatal Survival: An Indicator of a Functioning Health System in Delivering Maternal and Newborn Care

A functioning health system is needed to improve perinatal survival. For the first time, the Every Newborn Action Plan by the World Health Organization (WHO, 2014c) has brought together stillbirths and neonatal deaths into an integrated global health agenda. It highlights the need to strengthen health systems, and to address barriers to reduce the ongoing high rates of perinatal deaths in the developing countries. The linkage of perinatal survival with the health system is clearly described in the WHO framework to improve quality of maternal and newborn care at health facilities (WHO, 2017d). The framework shows a clear link of structure (health system), process (care provision, care receiving and crosscutting issues such as human resource and physical resource/logistics) and outcome (practices, survival and individual's satisfaction with the care).

Addressing health system barriers has been found to be critical based on the evidence that health facility based perinatal death audits have been a proven strategy to reduce perinatal deaths (Kerber et al., 2015; Pattinson et al., 2009). Quality of care audits help health facilities to timely identify and prevent avoidable factors in quality health care delivery to women and their babies. Such audits are strongly recommended for developing countries with high perinatal mortality. It is estimated that nearly one-third (30%) of perinatal deaths can be prevented by regularly conducting quality of care audits at health facility level (Pattinson et al., 2009).

Perinatal survival is considered as one of the key performance indicators of health care systems. Perinatal death is an outcome of poor quality of antenatal and perinatal care. Several studies (Bhutta, Darmstadt, Hasan, & Haws, 2005; Kerber et al., 2007; Marsh et al., 2002) have unequivocally stated that the survival chance of a baby in pregnancy and soon after birth is impacted by the quality of health care services provided during pregnancy, birth and the postnatal period. In addition, the most recently endorsed WHO strategy, the Every Newborn Action Plan

(ENAP) (WHO, 2014c) has laid out a continuum of care approach from pre-pregnancy to care after birth as essential components to prevent perinatal deaths. The World Health Organization has endorsed perinatal mortality, especially intrapartum stillbirth rate (rate of babies dying after onset of labour and before birth) as an indicator of poor quality of intrapartum care (WHO, 2014b), and the stillbirth rate is described as a marker of quality of care in pregnancy and childbirth (de Bernis et al., 2016). Despite the fact that almost all perinatal deaths are preventable, the rates and the magnitude of deaths still remain significantly high in Sub Saharan African and South Asian countries (Lawn et al., 2014; UNICEF, 2015b). These high death rates in the developing countries are often linked to their weak health systems (Dickson et al., 2014; Lawn, Cousens, & Zupan, 2005).

Equitable access to health care services during pregnancy, birth and immediately after birth are other indicators associated with the functioning of health care systems (Sharma et al., 2015). In fact, the importance of addressing barriers to strengthening health systems to deliver health care for mothers and their newborns has long been acknowledged (WHO, 2005), which however still remains unrealised in many developing countries. The focus has been largely on implementation of less integrated, often vertical health care projects in the hope of quick gains in maternal and child survival. A level of programmatic integration of health system components such as skilled health personnel and supplies became core elements in WHO's Integrated Management of Childhood Illness Strategy, now known as Integrated Management of Newborn and Childhood Illness (Costello & Dalglish, 2016). In developing countries, the delivery of such intervention packages is contingent upon a well-functioning primary health care system (district health system).

Receiving quality maternal and newborn care is now considered an entitlement of every pregnant woman and a newborn baby. Even today, universal access to quality maternal and newborn health services close to where women and families live remains a key challenge. Two recent significant research contributions in newborn survival: *The Lancet* 'Neonatal Survival Series' (Dickson et al., 2014) and the *BMC* 'Every Woman Every Newborn' supplement (Dickson et al., 2015) highlight health system bottlenecks as key factors to hinder the implementation of available essential neonatal interventions in South Asian and Sub Saharan African countries. These bottlenecks are the health system factors including community ownership, which have been key constraints to delivery of maternal and newborn care in health facilities and communities (Dickson et al., 2015). Addressing these constraints is essential to deliver pregnancy, childbirth and newborn care and to end every preventable perinatal death.

1.4 Socio-cultural Approach: Foundation in Public Health

Public health is the science of preventing disease, promoting health and prolonging life (Detels & Tan, 2015). Tod and Hirst (2014) discuss public health as a socio-cultural model, which is integral

to society, politics and culture. A public health approach to health issues emphasises the interaction of factors at individual, family, community, population and policy levels (Tod & Hirst, 2014; Ulin, Robinson, & Tolley, 2012). This approach is described as an integrated and multi-disciplinary approach, focusing on social and structural determinants that shape people's choice and negotiation for health and wellbeing. Baum (2016) discusses a new public health approach in which equity and social justice for people's health are the core underpinning values. In this regard, a public health approach is essentially a socio-cultural approach that is applied, and aims to focus on issues of practical relevance contributing to people's health and wellbeing.

Focus on social determinants of health has been an unequivocal priority to ensure people's health and wellbeing. The social model was embodied in the WHO's constitution in 1946, in its vision of global health as "a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity" (WHO, 2014a, p. 1). The concept of health is now understood as a dynamic process, including a spiritual dimension within it (WHO, 1999). The rise of community-based approaches in the 1960s and 70s was essentially to address the socio-cultural and environmental factors of poor health and survival (Irwin & Scali, 2010). More than high-tech/medical care, health education and disease prevention were at the heart of the community-based programmes where grassroots participation and empowerment to decision making in health were considered as a means to improving people's health.

The concept of comprehensive Primary Health Care (PHC) as a means to fair and good global health established at Alma Ata in 1978 (WHO, 1978), reaffirmed the importance of social determinants of health. Unacceptable health status in many developing countries and gap in health status between haves and have-nots are the key reasons behind the birth of the concept of PHC. Shortly after the Alma Ata conference, the ideals of PHC as adopted in the conference lost their vitality with the emergence of arguments in choosing between the selective versus comprehensive PHC (Walley et al., 2008). Providing health care in locally appropriate mode/technology, equity, people's participation, empowerment and self-reliance, and integration of care and collaboration with other related sectors, are key principles of comprehensive PHC (WHO, 1978). The comprehensive PHC approach has a core essence of empowering people and increasing their control over health. Such a comprehensive view of health care remained vertical, less integrated and often limited within bio-medical focus after the selective PHC argument. Walley et al. (2008) discussed that bottom-up support from empowered communities and top-down support from accountable governments can help to create an enabling environment to revitalise the ideals of PHC as set at the Alma Ata conference.

Within the context of maternal and child health, the social model of health and comprehensive PHC are about bringing health care close to the women and families in communities where they live and work. Furthermore, people's participation and local socio-cultural contexts are taken as the heart of

programme planning and implementation. Far from vertically implemented technical projects such as those currently seen in maternal and child health, focus in comprehensive PHC approach remains in correcting socio-economic and cultural conditions that produce vulnerabilities to poor health and survival. Health care is viewed at a larger scope, achieving health for all is considered as a means to socio-economic development.

A further affirmation on the importance of social determinants was evident in the first international conference on health promotion in November 1986 in Canada (WHO, 2009a). This conference drafted the Ottawa Charter for Health Promotion. The Ottawa charter emerged from the expectations of new public health movements around the world, and as a strategy to reach health for all (HFA) by the year 2000. The charter considered food, education, shelter, income, social justice and equity as fundamental prerequisites for good health. The key strategic activities of the charter include: community empowerment and participation in decision making about actions to improve and maintain health; enhancing life skills by education and learning opportunities at different settings such as home, community, schools; reorienting the health service towards health promotive actions; and to be responsive to local socio-cultural needs. This broader definition of health considers individuals and communities as key resources for their own health. Thus, the power to negotiate and have control over health is shifted from experts to the people and communities, from health for all to all for health. The spirit of Ottawa has been successively followed by conventions about health promotion held in Adelaide (1988), Thailand (2005), Nairobi (2009), Helsinki (2013) to the ninth conference in Shanghai (2016) (WHO, 2017b).

As a more consolidated action, WHO set up a Commission on Social Determinants of Health (CSDH) between 2005 and 2008.The commission aspired to an ambitious goal to close the gap (in health outcomes) in a generation by actions on social determinants of health (SDH). To this goal, the commission provided a conceptual framework for action on SDH (Figure 1.2), a framework that also guides the present study. The framework includes equity, human rights and distribution of power as core ethical values (Solar & Irwin, 2010). These values are the conceptual ideas on which the present thesis is based.

Figure 1.2 Conceptual framework for action on Social Determinants of Health

Source: Solar and Irwin (2010), WHO Commission on Social Determinants of Health, received permission to reproduce from WHO (ID: 236304)
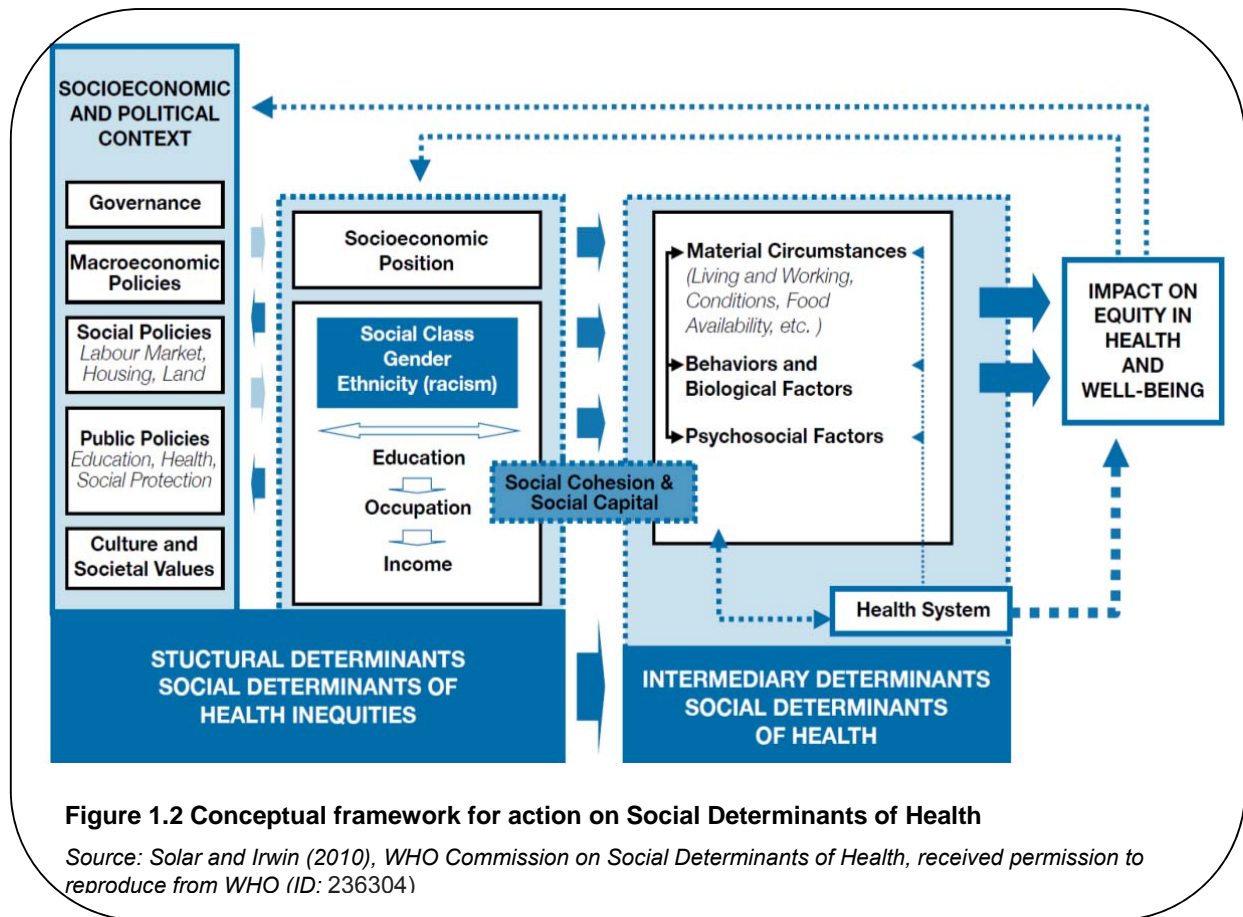
According to this framework (Figure 1.2), the health care system itself is viewed as a SDH. The health system is expected to play an important role in community participation and empowerment, in improving access to health care, and in reducing exposure and vulnerabilities to poor health. Health and health equity are seen as outcomes of social policies, and access to health care to be determined by factors in the socio-cultural environment. The health sector/ministries of health are directed to take a stewardship role to act towards SDH. Stated also in the commission's interim report, the WHO director, Margaret Chan said in her press statement (WHO, 2008) on the launch of the CSDH final report that addressing social determinants is addressing the 'causes of the causes'. Sources of ill health are considered to emerge from the conditions of daily life in which people are born, live, grow, work and age (CSDH, 2008). These in turn are affected by structural drivers such as distribution of resources, power and poverty. The daily living conditions, social processes (socio-economic and political contexts) and structural drivers embedded in social positions, class and hierarchy are together termed as social determinants of health inequities. Culture and societal values that include cultural factors and beliefs are included as social determinants of health inequities. The social position could be seen at individual, within family, community (group) and at a larger societal level. Gender, caste/ethnicity/race, income, education and occupation are common proxies used to define social position. The commission recommended three overarching action principles: (i) to improve daily living conditions; (ii) to tackle the structural

drivers of daily living conditions such as the inequitable distribution of resources, power, and poverty; and (iii) to begin to act and produce knowledge on social determinants at global, national and local levels. The commitment to addressing social determinants by reorienting the health sector towards health promotion and reduction of inequities is increasing even more after the WHO conference on SDH in Brazil (2011). This view is further supported in the post MDG development framework, the Social Development Goals (SDGs) (WHO, 2015a). In the SDG era, health is viewed as an outcome of a more inclusive and integrated approach across social, environmental and economic sectors.

The concept of socio-cultural and health care contexts in this thesis

Socio-cultural contexts in this thesis refer to the religio-cultural, and gender related cultural contexts that impact on the poor perinatal survival in the remote mountain villages of mid-western Nepal. Religio-cultural context refers to the socio-cultural values, beliefs and attitudes which are related to the local religious faiths, norms and practices. Likewise, gender related cultural context refers to the gendered norms, beliefs, values, gendered roles, access and control over pregnancy, birth and care of a baby that influences perinatal survival.

The health care context has been viewed within the socio-cultural approach. It refers to the contexts shaping health care access during pregnancy, birth and the postnatal period. It is about the context of delivery of essential care to a mother and baby in villages that impacts perinatal survival, at a primary health care system level, in a remote mountainous region of Nepal.

1.5 Perinatal Survival in Nepal: A Missing Consideration in the Rural Mountainous Region

Poor perinatal survival is one of the major public health problems in Nepal. Although Nepal is one of the few developing countries reaching its MDG child survival targets (MDG 4), and reaching close to MDG 5 targets in reducing maternal mortality (NPC, 2016; UNICEF and WHO, 2015), perinatal mortality rates are still high. More than 30,000 deaths (stillbirths and neonatal deaths) occur every year in Nepal (UNICEF and WHO, 2015).

The neonatal mortality rate was 33 per 1,000 livebirths according to the Nepal Demographic and Health Survey (NDHS) report published in 2012 (MOHP et al., 2012), the most recent national survey at the start of this study. It is still high at 21 (per 1,000 livebirths) according to a recently published NDHS indicators' report in 2017.[2] Perinatal mortality rate (stillbirths after 28 weeks to neonatal deaths up to 7 days after birth) is 37 per 1,000 births (MOHP et al., 2012). Of the total

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[2] Key indicators' report published in 2017, based on Nepal Demographic and Health Survey 2016.

neonatal deaths, more than one-third (35%) occurred on the first day, and more than four out of five (85%) occurred within the first week after birth (Paudel et al., 2013b).

More distinctively, Nepal's mountainous region has a very high neonatal (46 per 1,000 livebirths) and perinatal mortality rates (stillbirths after 28 weeks to neonatal deaths up to seven days after birth: > 40 per 1,000 births) (MOHP et al., 2012; Paudel et al., 2013a). These rates are equivalent to one of the highest rates in the world which come from Angola in Sub Saharan Africa, where the neonatal mortality rate is estimated at 49 per 1,000 livebirths (UNICEF, 2015b).

Although newborn survival has been a specific priority agenda in Nepal, the prevention of stillbirth is yet to become an integrated agenda together with newborn survival. Hence, the perinatal mortality rates are more likely to be underestimated. Within the regions, such as in the disadvantaged, rural and remote mountainous region of the country, underestimation is more likely to occur. The mortality rates are extrapolated and often based on national level surveys, without actually having subregional/district based data in the lack of proper reporting system for vital statistics. The perinatal mortality rates (PMRs) based on this study participants' report (who were voluntarily recruited) in the two mountain villages showed NMR 44 (per 1,000 livebirths), PMR 51 (stillbirths plus neonatal deaths in first 7 days of birth) and extended PMR 63 (stillbirths plus all neonatal deaths within first month) (see Chapter Four, Section 4.3.3, Box 4.1) for the last four years preceding the interviews. The mountainous region has similarly higher childhood mortality rates: infant below 12 months (National: 46, Mountain:73), and under-five mortality rate (National:54, Mountain:87) (MOHP et al., 2012).

Despite Nepal's national policies on maternal and newborn health (MOHP, 2004b, 2006a, 2006b, 2007) to increase access to skilled care during pregnancy, birth and postnatal period, the uptake of basic maternal and newborn care is not satisfactory. These policies intended to target disadvantaged and rural areas; to mobilise women and communities to increase demand for maternal and newborn care; to increase access to skilled care by mobilising SBAs and expanding rural birthing units; and to encourage women to attend health facilities for childbirths by providing cash incentives. Despite these attempts, the utilisation of basic care before and during pregnancy, skilled attendance at birth, and postnatal contact for mother and baby is still low at the national level and lower in the mountainous region of the country. At national level, only half (50%) of Nepal's pregnant women make antenatal contact; about one-third (36%) give birth in the presence of skilled attendants (and the same in the health facilities); and slightly less than half (45%) pregnant women make postnatal contact (MOHP et al., 2012). The recent NDHS indicators report (MOHP, New ERA, & ICF International Inc., 2017) showed that these coverage indicators have slightly increased at national level, yet the gap between mountain versus national level continues, and the mountainous region continues to be the lowest performing ecological region in terms of maternal and child health indicators. The people in the mountainous region have lower access to

health care. According to a government report, in the mountain district under this study, less than one-third (29.6%) of the women make antenatal contact (visit); only a quarter of women (21.5%) have skilled attendants at birth (and the same for health institutional birth); and less than half (44%) are reported to have postnatal contact (visit) (Department of Health Services [DoHS], 2014).

A range of studies done in Nepal has focussed on describing medical causes of neonatal mortality and its distribution across socio-demographic attributes, predominantly from the plains *(Terai)* and semi-urban hilly regions of the country, which have comparatively better access to health care information and services compared with the mountainous region (Dahal, 2013; Deo et al., 2015; Dhakal, van Teijlingen, Raja, & Dhakal, 2011; Dhakwa et al., 2014; Khanal et al., 2011b; Manandhar et al., 2015; Manandhar et al., 2010; Paudel, Khanal, Acharya, & Adhikari, 2013c; Shah et al., 2015; Shrestha et al., 2006; Shrestha et al., 2012; Wagle, Sabroe, & Nielsen, 2004). Some of these studies only used medically focussed verbal autopsies describing infection and intra-partum related conditions, such as asphyxia and obstetric complications as key reasons for perinatal deaths (Dhakwa et al., 2014; Khanal et al., 2011b; Manandhar et al., 2015; Manandhar et al., 2010; Shrestha et al., 2006). Some are cross-sectional quantitative surveys limited to describing the pattern of pregnancy, childbirth and postnatal service utilisation (Dahal, 2013; Deo et al., 2015; Dhakal et al., 2011; Paudel et al., 2013c; Shah et al., 2015; Shrestha et al., 2012; Wagle et al., 2004). Yet, all of these studies are from the plains *(Terai)* and semi-urban hilly regions. Other studies, based on national demographic and health survey (NDHS) data, described the pattern of neonatal mortality and its distribution across the country (Paudel et al., 2013a; Paudel et al., 2013b). As mentioned before, the data from the NDHS report the level of neonatal mortality as high in the rural, poor, low educated, disadvantaged and indigenous caste/ethnicity, and in the mountainous region of the country (MOHP et al., 2012). Both literature and available reports lack an in-depth examination of socio-cultural and health care contexts in relation to pregnancy, childbirth and newborn health.

In-depth qualitative studies examining the contexts of perinatal deaths are lacking in Nepal. A few qualitative studies conducted in the capital city, hills and plains regions neighbouring to the capital city, mainly involved hospital staff perspectives to explore delays in care seeking, and described husband and mothers-in-law as crucial in having an impact on the utilisation of pregnancy and childbirth services (Milne, van Teijlingen, Hundley, Simkhada, & Ireland, 2015; Morrison et al., 2014; Simkhada, Porter, & van Teijlingen, 2010). The only two studies known from the mountainous region: one relatively earlier study, a predominantly quantitative survey with added focus group (Thapa, Chongsuvivatwong, Geater, Ulstein, & Bechtel, 2000) and a more recent qualitative study by Kaphle et al. (2013) indicate that there is greater room for better understanding of factors behind high neonatal and infant deaths in the mountainous region. More specifically, perinatal deaths, considering both the stillbirths and neonatal deaths, are not a subject of investigation in these studies. The authors argued that a different culture, local dialects, structural

and other challenges in reaching care and reducing maternal and infant deaths are complex and remain largely overlooked in the context of women and families living in mountain areas.

Therefore, a high perinatal mortality combined with a low service uptake by women in the mountainous region warrants an in-depth investigation to explore the factors that influence perinatal survival. Understanding local socio-cultural and health care contexts of the disadvantaged rural mountainous region also aligns with the current international policy focus on equity, quality and coverage gaps to improve perinatal survival (Bhutta et al., 2014; Dickson et al., 2015), and the calls to reach every mother and every newborn (Every Woman Every Child, 2015; WHO, 2014c) to end preventable stillbirths and neonatal deaths.

1.6 Research Aim, Questions and Objectives

Aim of the study

This study aimed to explore and examine the contexts of poor perinatal survival—the socio-cultural and health care contexts in rural mountain villages of Nepal. The research uncovers these contexts taking the views and experiences of women and their families into the account. The research also involves the accounts of frontline health service providers including the female community health volunteers, and key local stakeholders such as faith healers, women activists, local journalists and staff working in non-governmental organisations.

Research question

The key research questions of this study are:

- Why is perinatal mortality in the rural mountainous region of Nepal high? Followed by, what factors influence perinatal survival in Nepal's rural mountainous region and how do they interact?

Study objectives

To understand the issue of poor perinatal survival in the mountainous region, this study sought to explore and examine the following objectives.

1. To explore women's and their family members' experiences and beliefs about perinatal sickness and deaths;
2. To examine the socio-cultural context of motherhood experiences (pregnancy and childbirth) and poor perinatal survival;
3. To examine health care delivery contexts of poor perinatal survival at a primary health care level; and

4. To consider the implications for health policy development and implementation in rural mountain villages.

1.7 Thesis Structure

The thesis is structured as follows:

Chapter One outlines the thesis with an introduction to the topic of the investigation, definition of relevant terms, the need and rationale for a socio-cultural focus, research aim, question, objectives and the structure of the entire thesis.

Chapter Two summarises key research and policy documents in order to expand the understanding about health care and socio-cultural contexts for improving poor perinatal survival. It provides an overview of what is already known about perinatal deaths: the significance and magnitude of perinatal death, the causes of the problem (medical causes and social determinants), and the proven interventions to end preventable deaths using available literature. The chapter also provides an overview of commonly used child survival related models/frameworks and concludes with the theoretical concepts shaping this thesis.

Chapter Three describes the methodological approach employed in this thesis.

Chapter Four provides a brief context of the fieldwork and the study area covering the socio-economic and living contexts and health care system in the mountain villages.

Chapter Five provides a critical account of Nepal's policy strategies, which have shaped the provision of health care to improve poor perinatal survival in rural and remote villages. This chapter serves as a basis to discuss perceptions and experiences of women and families, and the observation of health facilities in the villages.

Chapters Six, Seven and Eight describe and discuss the findings from the data collected from the study villages. Each chapter presents one of the three key themes: a) fatalistic beliefs about, and acceptance of perinatal sickness and deaths; b) gendered social constructs of motherhood and poor perinatal survival; c) declining standard of Primary Health Care and health system failures

Chapter Nine provides an overall discussion, a summary of potential implications and a brief conclusion to the thesis.

Note: A glossary of key Nepali-English terms has been provided in Appendix Six

1.8 Conclusion

This chapter has presented a background for the thesis. It has introduced poor perinatal survival, a public health problem linked to socio-cultural and health systems improvement. Poor perinatal survival is a public health problem and a national research priority agenda item in Nepal. There are ranges of cross-sectional studies and a few qualitative studies about pregnancy and childbirth located mainly in urban and semi-urban hills and plains *(Terai)* regions of Nepal. Studies focussed on the mountainous region of the country that bears the highest perinatal mortality rates in Nepal are lacking. This chapter provided the background for the study's aims and objectives to conduct in-depth contextual examination of the factors and their interactions in socio-cultural and health care contexts in shaping the persistently high perinatal death rates and vulnerabilities in the disadvantaged mountainous region. The chapter concluded with the overall structure of the thesis.

The next chapter presents a review of the literature to expand one's understanding of health systems and socio-cultural views about perinatal survival focussing mainly on developing countries.

REVIEW OF LITERATURE: HEALTH SYSTEMS AND SOCIO-CULTURAL VIEWS TO IMPROVE POOR PERINATAL SURVIVAL

The previous chapter presented the foundation for this research. As mentioned earlier, poor perinatal survival in Nepal is a significant public health problem and has strong links to socio-cultural determinants and health systems performances. The present chapter contains a review of relevant literature and begins with an explanation of the general protocol used for the review, followed by a global picture of perinatal deaths. It attempts to provide an overview of current research and global initiatives in preventing perinatal deaths, and available interventions to improve perinatal survival. The chapter also provides a broader understanding of socio-cultural and health systems determinants that affect perinatal survival in developing countries. Finally, the chapter ends with a brief review of theoretical concepts and frameworks/models used in child survival including social constructionism and critical theoretical perspectives that underpin this study.

2.1 Literature Search and Synthesis

The literature search aimed to identify, critically analyse and synthesise key international evidence about improving perinatal survival: survival of foetus—babies in pregnancies, as well as newborns after birth. Literature that describes, indicates or discusses the influence of local socio-cultural contexts and health system issues in health care utilisation, care practice during pregnancy, childbirth, and outcomes (positively or negatively impacting on perinatal survival) has been of primary focus. The most relevant academic papers, policy documents and grey literature describing health care and socio-cultural contexts and their influence on preventing perinatal deaths particularly in relation to developing countries, have been included. Literature has been searched using the following major electronic databases: Medline, Scopus, Popline, Web of Science, and Cochrane Library to include both the public health and social science related literature.

The following list of key terms and their combinations using Boolean logic (Havard, 2007) were used to search the literature. The Boolean logic helped to focus the search by developing strings/terms combining them with AND, OR, or NOT.

- Perinatal (neonatal, newborn, foetal, early infant);
- Experience (beliefs, culture, opinions, views, feelings, perceptions);

- Mortality, deaths, stillbirths, survival, sickness, illness);
- Context (developing countries, mountainous region, rural women, rural villages).

Literature published in English and Nepali has been included. Priority was given to include the most recent papers published in the last decade. Hand searches of reference lists of published papers and websites of key organisations have also been undertaken. The grey literature included government reports, electronic documents and study or programme progress reports of international agencies: WHO, UNICEF, United Nations Population Fund (UNFPA), Save the Children, Ministry of Health and Population Nepal, and online portals of Countdown to 2030-maternal, newborn and child survival, Healthy Newborn Network (HNN) and the Partnership for Maternal, Newborn and Child Health (PMNCH) alliance. There is an abundance of literature published in the field of maternal and child health. Therefore, studies proven to demonstrate a significant importance to draw global attention in the field of preventing perinatal deaths in low and middle-income countries have been keys to this review. Key attention has been given to include comprehensive series of papers in relation to perinatal death published in *The Lancet* (global health series—stillbirths and newborn survival), and *Bio-Med Central Pregnancy and Childbirth*: *Every Woman and Every Newborn* series which has had a major influence in informing and guiding current perinatal survival movements throughout developing countries.

2.2 Global Picture of Perinatal Deaths: Inequity and Injustice

2.2.1   High Magnitude and Unequal Distribution

Poor perinatal survival is a global public health issue. Globally, more than 14,500 deaths occur every day comprising stillbirths and neonatal deaths (Table 2.1).

Table 2.1 Global picture of perinatal deaths in 2015

Mortality rates/Deaths	Global	Developed Countries	Developing Countries
Neonatal deaths[1] (Number)	7,397 every day (2.7 million annually)	<1%	99%
Neonatal mortality rate[2] (per 1,000 livebirths)	21	3	21
Stillbirths[3] (Number)	7,178 every day (2.6 million annually)	<2%	98%
Stillbirth rate[4] (per 1,000 live and stillbirths)	19	3	19

Source: [1]WHO (2017a); [2]UNICEF (2015b); [3]WHO (2017c); [4]Blencowe et al. (2016)

According to the UN Inter-agency Group for Child Mortality Estimation (UNICEF, 2015b), the 2015 global average neonatal mortality rate is estimated at 19, infant mortality rate at 36 and under-five mortality rate at 43 per 1,000 livebirths. More than two-thirds of neonatal deaths are deaths within

a week after birth. Annually, one million neonatal deaths occur on the day after birth, and two million deaths within the first week after birth (Lawn et al., 2014). Worldwide, within the total under-five deaths, the share of the neonatal deaths is increasing—comprising nearly half of the total under-five deaths and about 60% of infant deaths (UNICEF, 2015b). The proportion of neonatal deaths within the infant and under-five mortality is increasing further in many developing countries. Likewise, nearly half (1.3 million) of stillbirths occur after the onset of labour, almost all in developing countries (Lawn et al., 2016).

Perinatal mortality is distributed unevenly between and within countries. Amongst developing countries, more than three-quarters of stillbirths (77.3%) (Blencowe et al., 2016) and neonatal deaths (UNICEF, 2015b) occur in Sub Saharan and South Asian countries. The Sub Saharan countries have the highest perinatal mortality rates. The South Asian countries record the greatest absolute number of perinatal deaths in the world. Sub Saharan and South Asian countries together constitute three-quarters of all infant and under-five deaths (UNICEF, 2015b). There is a lack of national mortality estimates within many developing countries. Estimates of stillbirths at sub-country level are still lacking, which indicates a continued low priority and negligence in preventing stillbirths, and therefore a high likelihood of a persistent occurrence in developing countries, concentrated mainly in rural and disadvantaged sub-country regions. Of the less than 1% of global stillbirths occurring in developed countries, these are mostly antepartum stillbirths related to physiological and congenital malformations (Lawn et al., 2014). Conversely, a large proportion of intrapartum stillbirths occur in developing countries.

2.2.2 Slow Progress in Reducing Perinatal Mortality

Since 1990, despite some progress in reducing overall child mortality rates, the trend in neonatal death reduction has been very slow compared with the rate of reduction in infant, post-neonatal and under-five mortality (UNICEF, 2015b; WHO, 2014c). Globally, between the 1990s and 2012, under-five mortality (per 1,000 livebirths) declined annually by 3%, while the neonatal mortality rate (per 1,000 live-births) reduced by only 2% during the same time period (WHO, 2014c). The progress in reducing stillbirth has been even slower. Calculations based on data for 2000 to 2009 showed an annual reduction only by 1.3%. Stillbirth remains a neglected priority in many countries (WHO, 2014c). Many developing countries need to double their current annual rates of reduction of perinatal mortality to meet the global and national targets of WHO Every Newborn Action Plan (ENAP) (WHO, 2014c). The ENAP target is to reduce perinatal mortality rates to 10 or less (per 1,000 livebirths) in each country resulting in a global average (for both the developed and developing countries) of 7 (per 1,000 livebirths) by the year 2035.

The Sub Saharan and South Asian countries have made limited progress in reducing perinatal mortality rates in the past 15-20 years (Lawn et al., 2014). These countries have weak health systems, and poor coverage of the maternal and neonatal care within communities (Darmstadt et

al., 2014). At 2.7% annual rate of neonatal mortality reduction between 2000 to 2012, it is estimated that it will take 110 years for an African and about 80 years for a South Asian woman to experience a similar chance of saving their newborn baby as is currently occurring for women from developed countries (Lawn et al., 2014). Moreover, at current rates of stillbirth reduction, about 100 years and 160 years respectively will pass for an average pregnant woman from South Asia and Africa before they experience a similar chance of saving their baby (preventing stillbirth) and catch up with the current situation in a developed country (Lawn et al., 2016). The perinatal mortality figures of the Sub Saharan African and the South Asian countries at present resemble the situation in developed countries in the 1950s or even earlier. Such a high mortality burden indicates that there is a lot to be done in terms of improving poor perinatal survival in these countries.

2.2.3 Perinatal Survival: A Matter of Justice and Children's Rights

Poor perinatal survival is a matter of justice and children's rights. The rights to survival, highest attainable standards of health, and development of every child under 18, are enshrined as fundamental rights of every child as ratified in the UN Convention on the Rights of the Child (UNICEF, 1989). Implicit in the convention, the rights of the children extended further to newborn children. However, prevention of stillbirths is not identified within this jurisdiction of child rights. Prevention of stillbirths remains as an ethical question entangled in the politics of induced abortion and reproductive rights (Frøen et al., 2011). This is an ethical question of when a life is considered worth saving. Recently, there is growing concern regarding the need to count and humanise stillbirths. A convergence has started in integrating stillbirths and neonatal deaths especially after the introduction of the WHO Every Newborn Action Plan (ENAP) (WHO, 2014c) (to be discussed further in Section 2.5.3). Subsequently, a discourse has started in humanising stillbirths, considering them as deaths of babies and ending every preventable stillbirth along with neonatal deaths (Frøen et al., 2016).

2.2.4 Burden of Poor Perinatal Survival: Huge Psychological and Socio-economic Consequences

Poor perinatal survival has huge psychological and socio-economic consequences. Each death puts parents and their family members in an emotionally difficult situation. Every year, millions of families suffer from grief and stigma due to stillbirths (Frøen et al., 2011) and loss of their newborns (Lawn et al., 2014). One in every five mothers suffers from depression, long-term anxiety and post-traumatic stress disorders after a stillborn baby (Frøen et al., 2011). Likewise, many fathers also suffer psychosocial consequences as a result of stillbirth and neonatal death (Badenhorst, Riches, Turton, & Hughes, 2006; Turton et al., 2006). Women suffer from the fear of shame, guilt and stigma which prevents them from openly sharing such experiences with their neighbours in their communities (Haws et al., 2010). The death of a newborn can perpetuate depression, stress, poor emotional health and also anxiety for women, which can reduce their

confidence, and can induce anxiety during their next pregnancies as well (Armstrong, 2004; Cǒté-Arsenault & Mahlangu, 1999).

It is estimated that perinatal conditions incur 10% of the global burden of disease (WHO, 2014c). Compared with the leading causes of deaths across all age groups, neonatal conditions (pre-term birth and asphyxia) rank within the top ten major causes of deaths in the low income countries (WHO, 2017d). Globally, the total death tolls due to all neonatal conditions (asphyxia, pre-term, infections and other conditions) is larger than the total number of deaths as a result of HIV/AIDs, Tuberculosis, parasitic and vector borne diseases, diarrhoeal diseases, maternal conditions and nutrition deficiencies (WHO, 2017d).

Poor perinatal conditions incur major economic consequences and social cost. The economic burden is related to treatment of sickness and related complications, disabilities and loss of potential in later lives (Lawn et al., 2014). Governments and families have to invest scarce resources in health care to cure and treat maternal and neonatal sicknesses. Poor families in developing countries are hit the hardest—loss of their time to care for sick babies and health care costs. Referral and treatment of a maternal and neonatal complication is a heavy cost burden on poor families in developing countries, more strongly in rural and remote areas within these countries. Even simple treatable childbirth conditions are likely to worsen and lead to a poor quality of life for thousands of women. The loss in overall quality of life and productivity of a woman suffering birth related complications such as fistula (Lawn et al., 2014) reflects the worst consequence. Considering this high cost of care and the implications of poor health during the perinatal period, the review of WHO Division on Macro-economics and Health (Gelband et al., 2001) called governments to address perinatal health in order to achieve sustained socio-economic development in countries across the world.

Along with ongoing high perinatal death tolls, additional economic burdens are likely to be due to loss of healthy human capital. Evidence suggests that babies with poor foetal growth and subsequent low birth weight are more susceptible to chronic diseases such as diabetes, hypertension and cardiovascular problems (Godfrey & Barker, 2000). WHO (1998b) estimated that for every neonatal death due to asphyxia, another child suffers with lifelong impairments such as epilepsy, cerebral palsy or developmental delay. Thousands of babies are estimated to suffer from reduced human potential due to neuro-developmental impairments from pre-term and associated complications of encephalopathy, meningitis and tetanus, labour complications, jaundice, neurocognitive loss in stunted children due to pre-term complications, and as adults with non-communicable diseases related to pre-term birth. Lawn et al. (2014) estimated that by 2035, failure to further improve birth outcomes would cause 116 million neonatal deaths globally, 99 million surviving with disability or loss of potential and additional millions of adults with increased risk of non-communicable disease in their later lives.

To summarise, perinatal conditions account for a significant burden of morbidity and mortality. These situations cause great social and economic loss, and the morbidities and mortalities reflect the existing injustices in countries and their communities—mostly affecting developing countries of South Asia and the Sub Saharan African region. This clearly implies the need for further actions to prevent ongoing perinatal deaths in these countries.

2.3 Key Global Initiatives and Research in Preventing Perinatal Deaths

The previous section described the global picture of perinatal deaths—the unequal distribution between and within countries. The section showed evidence of slow progress in reducing perinatal mortality and provided insights into the burdens and consequences of ongoing perinatal death including socio-economic, psychological and cognitive (human potential).

To tackle the problem of high perinatal mortality, a wide range of policies and programmes have been recommended by international organisations for implementation at national or sub-national levels. This section presents a brief chronology of key global initiatives and research that has shaped perinatal survival policies and interventions in developing countries. Figure 2.1 provides a comprehensive overview of major global actions towards a better understanding of, and strategies of actions to address, the high prevalence of perinatal mortality with a main emphasis on developing countries.

Following the schematic overview, Table 2.2 provides brief comments/focus areas, key gaps and recommendations from the initiatives and research.

Major Global Health Initiatives **Research Activities**

| Primary Health Care, Alma Ata, 1978 | Child Survival Revolution, UNICEF, 1980s | World Summit for Children, UNICEF, 1990 | World Millennium Summit, UN, 2000 | Sustainable Development Goals, UN, 2015 | Bellagio Child Survival Series, The Lancet 2003 | Neonatal Survival Series, The Lancet 2005 | Stillbirth Series, The Lancet 2011 | Every Newborn Series, The Lancet 2014 | Every Woman Every Child Series, BMC 2015 | Ending Stillbirths, The Lancet 2016 |

➢ No specific priority, the high proportion of **neonatal deaths among the total under-five deaths, newborn survival begins to emerge as an agenda** item in policy strategies after the pressing need to reach the MDG under-five mortality target. Stillbirths remain invisible.

➢ Evidence primarily describes the **epidemiology** (who, where, when and what interventions) of perinatal deaths. After 2014, the evidence discourse in contributing to reduce perinatal deaths has focussed on identifying/exploring **health systems failures**, which create obstacles in delivering health care and its access by every women and every newborn.

➢ Discourse moving towards equity, integration of interventions to reduce stillbirths and newborn deaths, increasing focus towards socio-cultural determinants, reaching everyone and ending all preventable deaths.

Figure 2.1 Overview of key global initiatives and research, and prevention of perinatal deaths

Table 2.2 Summary of major global initiatives/research series, and prevention of perinatal deaths

Date	Title of the Initiative/Research Series	Brief comments/Focus Areas	Key gaps identified	Key recommendations/suggestions discussed
1978	Primary Health Care, Alma Ata	• Universal health care (health for all) • Main focus on maternal and child health (MCH), family planning, and health education • Prevention and treatment of common diseases, immunisation, nutrition	• No explicit mention of neonatal and stillbirths as priority agenda within maternal and child health	• Focus on Comprehensive Primary Health care • Emphasise community engagement, inter-sectoral coordination, prevention and promotive health • Focus on equity • Address social determinants of health and community development • Focus on locally tailored interventions
1980s	UNICEF Child Survival Revolution	• GOBI 3Fs: Growth monitoring, Oral Rehydration Solution, Breastfeeding and Immunisation (UNICEF, 2008). Later, three additional components, 3Fs: female education, family planning and food were added and advocated as GOBI 3Fs to prevent ongoing child mortalities	• No explicit mention of neonatal death and stillbirths	• Emphasises Selective Primary Health care Approach • Advocates a targeted approach to address under-five child deaths
1990	World Summit for Children	• Focus on child rights: survival, protection, development and participation • Key focus on preventing under-five mortality	• In the midst of fighting for survival of older infants (post-neonatal) and under-five children, prevention of stillbirths and neonatal deaths were still missed from global health priorities	• Advocates child survival, protection, development and participation as fundamental child rights • Sets specific targets to reduce under-five and infant mortalities by 2000
2000	Millennium Development Goal	• Eight sectoral goals including maternal health (Goal 5), child mortality (Goal 4), and gender equality and women empowerment (Goal 3) as most related to perinatal health • Emerging focus on neonatal survival mainly due to pressing targets to reduce under-five mortality	• Some of the criticisms are: vertical approach of programming; number oriented-emphasising mainly about measuring targets (at national level), a one-size fits all development approach, poor attention to health systems	• Recognises neonatal deaths as a large contributor to under-five mortality (>40%) • Calls for country level policies and strategies to address neonatal death

			strengthening and in-country inequities (WHO, 2015a) • Prevention of stillbirth still remained neglected in policies and programmes	
2003	Bellagio Child Survival Series, *The Lancet* 2003 [5 papers]	• Focus on the causes of and intervention to tackle under-five mortality	• A beginning to separately acknowledge the poor neonatal survival, but stillbirths did still not become an area of programme and research priority	• Suggests a list of 23 interventions: 15 preventive and eight treatment interventions to reduce under-five mortality (Jones, Steketee, Black, Bhutta, & Morris, 2003) • Identifies that the suggested interventions are also effective to reduce up to 55% neonatal deaths • Strengthen health systems (Bryce et al., 2003) and consider equity as more effective than any intervention or combination of interventions (Victora et al., 2003) to contribute to reduce child mortality
2005	Neonatal Survival Series, *The Lancet* 2005 [4 papers]	• First systematic analysis of global status of neonatal survival • Describes causes, distribution and interventions to reduce neonatal deaths • Focus on describing rates, size of the neonatal deaths (annually 4 million), inequitable distribution (developed: 1% versus developing countries: 99%), timing of neonatal deaths (during and immediately after birth) and causes (pre-term birth, infection and asphyxia as leading causes) • Describes a range of essential newborn interventions in continuum of pregnancy to postnatal, and home/family to health facilities	• Poor access to interventions contributes to 70% of neonatal deaths (Knippenberg et al., 2005) • Knowledge gaps in improving care seeking for sickness, content and timing of postnatal care, and in measurement of community engagement and demand for essential newborn care	• Suggests a list of 16 proven interventions across the pregnancy to postnatal continuum (Darmstadt et al., 2005) • Recommends outreach (community visits), family/community-based (mobilisation and engagement) and health facility based care (skilled care for mother and newborn) • Low-tech care (home based and community care) without intensive care units can help to reduce neonatal mortality. Countries are no longer required to wait until post-neonatal mortality drops

				• Suggests data based decision making and equity/right based policy process
2011	Stillbirths Series, *The Lancet* 2011 [6 papers]	• The consequences of stillbirths: psychological burden, stigma, blame and marginalisation of millions of women and families (Frøen et al., 2011) • Epidemiology of stillbirths (Lawn et al., 2011): rates (varies between less than 4 in developed countries to more than 40 in developing countries; number (2.65 million every year), timing (half of the total stillbirths during labour) and where (98% in developing countries, 67% in their rural areas) • Interventions: both medical and social interventions; interventions around birth are estimated to prevent nearly half (45%) of the stillbirths (Bhutta et al., 2011)	• Research gap on 'How to mobilise communities effectively to make their efforts count' and 'How to improve support for women and families with a stillbirth and remove the associated stigma' (Goldenberg et al., 2011, p. 1801) • Barriers to avert stillbirths remain little explored	• Emphasise stillbirths as a part of public health agenda (Frøen et al., 2011) • Suggests a list of 10 stronger and 35 potential interventions (Bhutta et al., 2011) to manage birth complications, improving skilled care at birth, treating maternal infections, and improving quality antenatal care and birth spacing • Integrate stillbirths with current maternal and newborn health interventions, and to reinforce birth as a window to prevent a large number of maternal deaths, neonatal deaths and stillbirths • Community mobilisation
2014	Every Newborn Series, *The Lancet* 2014 [5 papers]	• Recognition of newborn survival and stillbirth prevention as priority national and international policy agenda • Reaffirms the evidence regarding epidemiology of stillbirths and neonatal deaths (Lawn et al., 2014): when (during birth and on the first day, 73% neonatal deaths on the first week), where (99% in developing countries—mostly in Sub Sahara and South Asia) and why (intrapartum complication, prematurity related complications and infection) • Discusses concern for equity gaps (mainly of rich and poor) and health system strengthening to contribute to reduce stillbirths and neonatal deaths	• Access gaps: multiple initiatives, partnerships and policy strategies emerged at national level (Darmstadt et al., 2014) • However, a large proportion of mother and babies remain to access available interventions particularly due to health system constraints in delivering care • Quality gaps in rendering skilled care for mothers and babies (particularly during and immediately after birth)—quality care during and after 48 hours of birth is estimated to prevent 40%	• Focus on equity and health systems strengthening to contribute to delivering available interventions • Integrate prevention of stillbirths and neonatal deaths • Reaffirms care along the continua (pre-pregnancy and postnatal, and home to health facility) • Generate local data, bring social and behavioural changes to the communities, provide greater support to community health workers and develop a strong linkage between community and health facilities • Suggests a comprehensive framework

			neonatal deaths (Lawn et al., 2014)		for action along the pre-pregnancy to postnatal continuum with a key emphasis on the time around birth to address quality gaps
			• Equity gaps to reach the poor, rural, disadvantaged and hard-to reach areas. According to 2012 data, estimation shows that about 40% neonatal deaths could be prevented if risks among the poorest 20% were similar to the top 20% of people in India, Nepal, Bangladesh, Philippines, Cambodia and Bolivia (Lawn et al., 2014)		• Engage civil society and mobilise parent groups. Family/community-based interventions and immediate care of newborns is estimated to prevent about 400,000 deaths by 2020 (Bhutta et al., 2014)
			• Lack of local data and poor community and health facility linkages		
2015	Every Woman Every Newborn, *BioMed Central* 2015 [9 papers]	• A further exploration of health systems bottlenecks as recommended in *The Lancet* 2014 'Every Newborn Series' • Factors hindering delivery of health care and contributing to poor perinatal survival are seen across the elements of health systems • The bottlenecks have been graded (as no, minor, significant and major) and described across health system building blocks including community ownership • Specific bottlenecks concerning high impact interventions around birth: quality of care at birth (labour and immediate newborn care) (Enweronu-Laryea et al., 2015; Liu et al., 2015; Sharma et al., 2015); care of small and sick newborns (Moxon et al., 2015a; Simen-Kapeu et al., 2015; Vesel et al., 2015); and measurement and accountability (Kerber et al., 2015; Moxon et al., 2015b)	• Rather than an in-depth examination, the bottlenecks have been graded and described based on experts' (health professionals) experiences and suggestions at country level workshops • It lacks views and experiences of women and families about what has hindered them to access health care		• Specific bottlenecks in health systems must be addressed to reach every mother and every newborn • Significant or major bottlenecks remain in health service delivery (basic and comprehensive obstetric complications, basic newborn care), health financing and health workforce related to training and deployment of SBAs; competency in treatment of neonatal infections; and inpatient care of small and sick newborns • Community ownership and partnership to promote women and families in seeking care and treatment for neonatal infections and small and sick newborns (Dickson et al., 2015; Moxon et al., 2015a; Simen-Kapeu et al., 2015)

Year				
				• Low awareness, stigma, fatalism and low male involvement as constraints to community ownership
2015	Social Development Goals	• Post 2015 development framework, 17 SDGs • Focus on equity • Ending preventable neonatal deaths by 2030 is the number three target under the SDG health goal (Goal 3) • Closely related to perinatal survival are gender equality (Goal 5), reducing inequity between and within countries (Goal 10)	• Ending preventable neonatal deaths for the first time has been set as a specific target in SDG health goal. Still, the plan did not specifically talk about stillbirth	• Commitments to population health, health equity and social determinants of health • Reach everyone, leave no one behind • End all preventable neonatal deaths
2016	Ending Preventable Stillbirths, *The Lancet* 2016 [5 papers]	• A follow up of *The Lancet* 2011 Stillbirth Series • Emphasis on stillbirths, valuing stillbirths as 'babies dying' (Frøen et al., 2016) • Stillbirth as a marker of quality of care during pregnancy and childbirth (de Bernis et al., 2016) • Description of epidemiology (worldwide 2.6 million stillbirths, nearly half of which during labour, 98% in developing countries and 65% of which are in rural areas) (Lawn et al., 2016) • Up to 60% or even more stillbirths during labour in South Asian countries • Discuss economic and psychosocial burden of stillbirths on parents (Heazell et al., 2016) • Stigma and fatalism view among women in developing countries and low socio-economic groups of high-income countries—two times more likely to have a stillborn child than their counterparts (Flenady et al., 2016)	• Low priority given to prevention of stillbirth compared to neonatal death • A further slower annual rate of reduction of stillbirths compared to reduction in neonatal deaths • Poor engagement of women and families in research, prevention and support	• Humanise stillbirths • Needs to double (4.2%) from the average 2% annual reduction seen in between 2000 and 2015 (Lawn et al., 2016) • Contextual and respectful care of women to reduce the burden due to stigma • Health promotion along the continuum of women and children's health, integrated mother-baby dyad approach, and quality of care • "Engage women, families, and communities in research, prevention, support, and convening opportunities" (de Bernis et al., 2016, p. 712)

To summarise, the above research and global initiatives (Table 2.2) clearly indicates the following two major points:

➢ *A move from sole attention to maternal and child health in general to neonatal and stillbirths:*

The review of global initiatives and high impact research shows that the prevention of neonatal deaths and stillbirths are areas which have been mostly neglected within the broader maternal and child health programmes. Stillbirth in particular attracted least attention over time. However, with growing evidence on the high prevalence of stillbirths, and the causes and cost-effective interventions, the myths have been corrected (de Bernis et al., 2016). Arguments and calls have been made to integrate actions to reduce stillbirths and neonatal deaths within the maternal and child health programmes. To meet the WHO targets for ending preventable perinatal deaths by 2030 (WHO, 2014c), each country is invited to integrate efforts to end preventable stillbirths and neonatal deaths. A continuum of care across pre-pregnancy to postnatal has been the key approach to advance perinatal survival with a special focus on the time around birth. Further elaboration on the continuum approach is presented in Section 2.5.3.

➢ *A move from epidemiological views to more health system view, and attention to equity and community voice:*

The evidence generated by *The Lancet* 2014 'Every Newborn Series', *BMC* 2015 'Every Woman Every Newborn' series, and *The Lancet* 2016 'Ending Preventable Stillbirths' series, has strongly called for actions to reach every woman and newborn to end preventable perinatal deaths. Quality, coverage and equity have been emerging concerns in providing health care (Mason et al., 2014; WHO, 2014c). The actions as well as research priorities have shifted from solely epidemiological perspectives towards a better understanding of health systems constraints, from measuring targets at national level to paying attention to every single case of death and listening to the voices of women, families and communities. Yet, the research described above is predominantly based on views of experts (bio-medical causes) and service providers from policy/management level. Evidence shows that medical factors are known, and hence it clearly indicates international communities need to understand context specific factors hindering implementation of care, and factors that prevent access to health care by women and communities. Women, families, front-line primary health care workers, and communities' voices have been neglected. This evidence indicates that developing countries would require focusing on effective delivery of interventions to accelerate their progress in improving poor perinatal survival. Equity has been a key concern to improve perinatal survival. Disadvantaged population groups and in-country subregions with high mortality require urgent priority. Sections 2.5 and 2.6 add further understanding about socio-cultural and health system views in improving poor perinatal survival.

2.4 Interventions and Strategies: Effective Public Health Measures, Basic Primary Health Care and Continuum of Care

The previous section provided an overview of key initiatives and research related to the prevention of perinatal deaths. As outlined in Table 2.2, neither the MDGs nor any other UN agencies had incorporated the prevention of neonatal deaths and stillbirth as priority agendas in policy strategies. However, evidence which emerged from a series of scientific studies has shown that it is impossible to achieve under-five mortality targets without addressing the increasing proportion of neonatal deaths and that advocating newborn survival is crucial to reach the MDG under-five mortality target.

Expanding on the findings from the previous section, this section provides an overview of key interventions and strategies available to address poor perinatal survival focussing on a primary health care level.

2.4.1 Effective Public Health Measures

Evidence from the UK, cited in Lawn et al. (2005) and from Sweden (Andersson, Hogberg, & Bergstrom, 2000; Hogberg, 2004) suggests that a large number of perinatal deaths can be averted at a relatively low level of resources with effective community and outreach interventions. There are examples of successful programmes that have avoided expensive high-tech specialist care and Neonatal Intensive Care Units (NICUs). The significant reduction in neonatal mortality in the UK, from 30 (per 1,000 livebirths) to 10 between 1940 and 1977, was achieved largely through the public health measures of providing improved care during labour, home visits by midwives, and the provision of antibiotics, and free antenatal care (Lawn et al., 2005). Sweden reduced its perinatal mortality by 15% during 1881 to1890 and by 32% during 1891 to 1899 with outreach and community measures such as, use of midwives for homebirths, cord care, resuscitation with tactile stimulation, warmth, early breastfeeding and aseptic techniques (Andersson et al., 2000; Hogberg, 2004). Between 1871 and 1880, about 44% of Swedish mothers were homebirths attended by midwives and this increased to 74% by the end of the 19th century. Much earlier in 1711, Johan von Hoorn, the founder of the first midwifery school in Sweden cited in Andersson et al. (2000, p. 546) stated:

> Of 100 stillbirths, 80 could have been prevented if a competent midwife had been with them.
> My heart sheds tears of blood every time these innocent souls are lost in death.

This statement shows that the effectiveness of midwives' assistance in saving babies during childbirth was realised much earlier in Sweden. Andersson et al. (2000) stated that it was the midwife led homebirths that contributed to the 32% total perinatal mortality reduction during 1891 to 1899 in Sweden. The study shows that community midwives attended a majority of deliveries throughout Sweden. Deliveries by general practitioners were limited to major city hospitals in the urban areas that were occupied by less than 10% of the total Swedish population by the late 19th

century. Community midwives attended almost all home deliveries in rural areas. Along with the reductions in perinatal mortality, the community midwives were also regarded as the key to the successful reduction of Sweden's maternal mortality (Hogberg, 2004). It is noted that one of the success factors behind the effective Swedish maternity programme was also the effective management of the midwives at county level and their representation from different walks of life at local county level giving due care to the local cultural context.

It appears that similar interventions, applied in the contexts of developing countries could reduce their large numbers of continuing perinatal deaths. Some developing countries such as Indonesia, Honduras, Sri Lanka, Vietnam and Nicaragua are credited with achieving impressive reductions in neonatal mortality (Lawn et al., 2005; Martines et al., 2005). With no single specialised services such as NICUs, Sri Lanka was able to reduce its neonatal mortality from more than 75 (per 1,000 livebirths) in the 1940s to less than 20 (per 1,000 livebirths) by the mid-1980s. The establishment of the first NICU in Colombo hospital in the early 1990s and the addition of 40 incubators by the end of 1999 occurred after Sri Lanka achieved a significant reduction in its neonatal mortality rates. National welfare policy (free maternity care), government's commitment to primary health care (Orubuloye & Oyeneye, 1982), political commitment (Caldwell, 1986), priority given to disadvantaged and rural areas, effective implementation of community and outreach care with qualified midwives, and increased availability and accessibility of primary care centres and hospitals (within 5 kilometres radius) are described as the key contributors to the successful neonatal and maternal mortality reduction in Sri Lanka (Pathmanathan & Liljestrand, 2003). By 1999, Sri Lanka had 100% antenatal care (ANC) coverage, and 86% of deliveries were attended by skilled health workers by 1986 (Martines et al., 2005). Sri Lanka's high literacy rate (over 90% in both male and female) and the increased utilisation of the public sector outreach and primary care services are also considered key contributing factors to improved survival of mothers and newborns in the country (Pathmanathan & Liljestrand, 2003).

Sri Lanka implemented maternal and child health programmes that focused on improved access for people living in rural areas and disadvantaged conditions. This was undertaken within the context of a weak and underdeveloped health system. Then the focus shifted towards increased utilisation of health care and a simultaneous focus on quality improvement. It is noted that antenatal care, home visits and civil registration of births and deaths were effectively channelised to promote the use of skilled attendants by every woman and family. In 2015, Sri Lanka had a neonatal mortality rate of 5 (per 1,000 livebirths) and low infant (8 per 1,000 livebirths) and under-five (10 per 1,000 livebirths) mortalities (UNICEF, 2015b), the lowest rate in South Asia and one of the lowest rates among the developing countries across the world.

2.4.2 Family and Community Engagement and Basic Primary Health Care

Literature provides success stories from the South Asian countries on the effectiveness of interventions including community engagement and primary health care approaches in improving care utilisation and contributing to reduce perinatal mortalities. At country level, the case of Sri Lanka as discussed above, showed that effective linkage of home visits and antenatal care was one of the key factors to increase utilisation of skilled attendants during birth that contributed to the country's achievements in reducing maternal, infant and neonatal mortality rates. A recent review of randomised controlled trials (Gogia & Sachdev, 2016) discussing intervention sites at sub-country level in other South Asian countries, identified community-based care packages facilitated by community health workers as contributing to the reduction of neonatal deaths by 25% and stillbirths plus early neonatal deaths by 22%. The review included five controlled trials (intervention studies) conducted in India (two trials), Pakistan (one trial) and Bangladesh (two trials). The intervention packages comprised home visits during the antenatal, neonatal/postnatal period, community mobilisation, home based treatment of infection and referral. Of the five trials included in this review, one study conducted in Shivgarh, Uttar Pradesh in India (Kumar et al., 2008) showed a 49% reduction in neonatal mortality after 16 months of intervention between 2004 and 2005. Another trial conducted in Bangladesh (Baqui et al., 2009) showed a 34% decline in neonatal mortality rate after 24 months' intervention during 2004 and 2005.

A review of community-based implementation packages (Lassi & Bhutta, 2015) also revealed similar effects in reducing neonatal mortality (by 25%) and stillbirths (19%) in the intervention areas of South Asian countries. On sub-group analysis, the review by Lassi and Bhutta (2015) showed that the following community efforts had a significant impact in reducing neonatal mortality and stillbirths: formation of women's groups/community support groups; training of Traditional Birth Attendants and home visits during the antenatal and intrapartum period; and community mobilisation along with antenatal and postnatal home visits. Significant improvements in antenatal, childbirth and neonatal care practices were evident in both reviews (Gogia & Sachdev, 2016; Lassi & Bhutta, 2015). Evidence from these large-scale reviews confirms the effectiveness of community-based interventions in improving care practices and reducing mortality in poorly resourced countries with high rates of mortality.

Home based care with community health workers

A significant reduction in perinatal deaths became possible in one of the earlier community-based trials conducted in India (Bang et al., 2005). Neonatal mortality, stillbirths and perinatal mortality were reduced by 70%, 49% and 56% respectively in Gadchiroli district of Maharashtra, India in a period of 10 years from 1993 to 2003. In the intervention area, the neonatal mortality rate decreased from 62 to 25, both early neonatal (24 points) and post-neonatal (20 points). However, in the control area (47 villages), the situation continued to worsen, and the NMR of 58 in 1993-

1995 increased to 64 in 2001-2003. Overall, in Gadchiroli, the main interventions identified as successful were homebased neonatal care using frontline health workers that included behaviour change, encouraging mothers and families to seek care and to seek it more promptly, and providing health education and support from village health workers for managing sick newborns (Bang, Bang, Baitule, Reddy, & Deshmukh, 1999; Bang et al., 2005).

Participatory women's group mobilisation

As in Gadchiroli, India, a great success in reducing perinatal mortality rates was seen after implementing Bolivia's Warmi project (a before and after trial), which comprised facilitation of women's groups using a participatory action learning cycle about mother and infant care as the key intervention (O'Rourke, Howard-Grabman, & Seoane, 1998). The project covered a small rural and poor population of 15,000 with a weak health system. Over a period of three years, the project interventions enabled a reduction in perinatal mortality rate from 117 to 44 (per 1,000 births) which is a 62% reduction. Likewise, a community-based randomised trial conducted in an eastern district of Nepal (Manandhar et al., 2004) reduced neonatal mortality by 30% during 30 months of intervention (2001 to 2003) through community mobilisation with women's groups and joint planning and assessments. The intervention was conducted in Makawanpur that joins the central hills of Nepal with the southern plains region. It is a relatively accessible district adjoining the capital city, Kathmandu. The intervention comprised basic perinatal health and communication/facilitation skills training to the paid local women facilitators. Each facilitator facilitated nine women's group meetings every month in coordination with local female community health volunteers and health workers. The meetings were facilitated following an action-learning cycle to identify local perinatal problems and to formulate contextual strategies in order to improve home care practices and to increase utilisation of health facilities throughout pregnancy, birth and the postnatal/neonatal period. A supervisor in each meeting supported the woman facilitator. One supervisor was assigned to guide three woman facilitators. This women's group mobilisation with a local woman facilitator was implemented only in the intervention clusters (12 intervention clusters with approximate total population of 84,000). Throughout the district, in both the intervention and control clusters, the non-governmental organisation in partnership with the local District Health Office, facilitated essential newborn care training to all cadres of the primary health care system in the district, and ensured provision of essential newborn care supplies and logistics in health facilities. The women's group strategies included several activities such as active enrolment of all pregnant women in the catchment area; participatory discussions; initiation of local funds for emergencies; stretcher schemes, picture card games; and visits to educate, support and encourage any pregnant and recently delivered mothers in their catchment area.

It is worth noting that the impact of women's group mobilisation on neonatal mortality is not consistent. A participatory women's group intervention conducted in three rural districts of Bangladesh showed no effect in reducing neonatal mortality rates and health care seeking during

pregnancy, birth and mother and babies' sickness (Azad et al., 2010). In the Bangladesh study, the authors cite that effective implementation of their intervention could have been compromised due to their less intensive approach of women's group facilitation, relatively low support for facilitators, low focus on service delivery strategies and contextual factors such as women's low participation in meetings.

Although the earlier Makawanpur trial conducted in Nepal showed great success in improving care coverage and reducing neonatal deaths within 30 months of intervention (Manandhar et al., 2004), the newborn care packages piloted in a relatively larger geographical area covering 10 districts (both from plains and hilly regions) of Nepal did not achieve similar success (Paudel et al., 2013a). One of the reasons is argued to be the lack of similarly intensive participatory women's group mobilisation as facilitated by the non-Governmental Organisation—Mothers and Infant Research Activities, in the Makawanpur trial. The Makawnpur trial ensured an active enrolment of pregnant women, monthly group discussion and follow up home visits by facilitators, field interviewers as well as women's group members until after birth throughout the neonatal period. In addition to 30 months, the Makawanpur trial took more than one year (September 1999 to November 2004) of enrolment phase, which provided a foundation to include key targets: the married women of reproductive age and any pregnant women. Whereas, in the government's pilot of the newborn care package, the facilitation of mother's groups (similar to women's groups), community visits, ensuring logistics and supplies in health facilities remained up to the local health system (Paudel et al., 2013a). Another major point for not having a satisfactory result could be that the government's pilot lacked any formative research, which however made a basis for the Makawanpur trial.

Above all, the heart of the participatory women's group is participatory facilitation rather than a conventional instructive type of health education (Manandhar et al., 2004). Facilitation of a group depends on motivated, skilled and well-supported facilitators. In Nepal's government primary health care system, facilitating women and families participation and empowerment is up to female community health volunteers and staff of primary health care systems. Therefore, bringing a similar success at system level seems affected by a well-functioning primary health care system that values participatory health promotive approaches, women, families and community involvement and empowerment.

Community engagement

Community engagement and stakeholder mobilisation strategies have also proven effective in middle income countries with high neonatal mortality ranging from 15 to 30 (per 1,000 livebirths). A cluster randomised controlled trial in Quang Nanh Province of Vietnam (Persson et al., 2013) showed a reduction on neonatal mortality from 24 to 16.5 in a period of three years from 2009 to 2011. The intervention constituted facilitation of local stakeholders groups called Maternal and Neonatal Health Groups (MNHGs) including local politicians, lay women, and primary health care

staff (physician, nurse, midwife) through a Plan, Do, Study and Act (PDSA) cycle. The intervention started in 2008, and annual assessments conducted in 2009, 2010 and 2011 showed a downward time trend in mortality reduction. Neonatal mortality was reduced significantly in the third year in 2011 [Odds Ratio 0.51 (95% Confidence Interval 0.30–0.89)] in the intervention communes, but not in the control communes. In 2011, the neonatal mortality was recorded as 16.5 (per 1,000 livebirths) in the intervention area. With the PDSA cycle, the frequently identified problems were low awareness, high homebirths, poor postnatal and antenatal visits; and the actions frequently taken were education, communication and postnatal home visits. In the same trial, another study by Målqvist, Hoa, Persson, and Selling (2015) assessed that the MNHGs mobilisation was a pro-equity approach that contributed to the reduction of neonatal mortality by 69% among the poor mothers in the intervention areas as compared with the poor mothers in the control areas. Likewise, in the intervention communes, mothers with higher education had 50% lower risk of neonatal mortality.

Basic primary health care measures

Simple primary health care measures have been the most commonly recommended interventions to reach the UN MDGs in relation to improved newborn care and preventing neonatal deaths (Costello, Francis, Byrne, & Puddephatt, 2001; WHO, 1998a, 1998b). These include interventions, such as the provision of adequate nutrition, Tetanus Toxoid (TT) immunisation, screening and treatment for infections, health education and counselling for birth preparedness, early and exclusive breast feeding, skilled attendants and maintenance of hygiene and cleanliness during birth, keeping the baby warm (drying/wrapping, skin to skin contact with mother, delaying bath), and caring of babies' umbilicus to prevent infection. According to the WHO guidelines related to integrated management of pregnancy, childbirth and newborn care (WHO, 2015b), low birth weight (LBW) babies, asphyxiated babies and babies with recognised danger signs must receive immediate care, and families are encouraged to seek timely care from health facilities. Even today, such measures are equally relevant to reduce ongoing perinatal mortality in developing countries. These basic interventions are now suggested through integrated packages for mother, newborn and children's health (Bhutta et al., 2008). Simple interventions, such as optimal and early initiation of breastfeeding, contribute to reducing 55-87% of all cause neonatal mortality rate, and preventing hypothermia contributes up to 18-42% reduction in neonatal deaths (Bhutta et al., 2005). However, according to the State of the World's Children UNICEF (2014) report, only 43% of babies have immediate breastfeeding (breastfeeding within an hour) across the world, and only 41% in South Asia.

Outreach and family/community-based care are groups of interventions, which if expanded universally and implemented effectively, can reduce two of every five current global neonatal deaths (Bhutta et al., 2005). The effect of these interventions can be as high as 74% reduction in neonatal deaths if essential neonatal care interventions (facility, outreach, family-community) are

universally provided (Bhutta et al., 2014). Outreach care mainly comprises antenatal care, and the family-community care comprises family and community-based care that engages, empowers and enables families' and communities' self-care and healthy behaviour changes. These interventions also aim to increase care practices of families, including seeking and demanding care during illness. Other studies (Bhutta et al., 2005; Bhutta et al., 2014) have consistently shown that countries with high neonatal mortalities could make substantial progress by improving domiciliary neonatal care and care seeking, including prenatal care through family and community-based approaches. Increasing attention to warmth, feeding and prevention or early treatment of infections can save many moderately LBW babies and moderately pre-term babies (Lawn et al., 2005). Despite the evidence on the cost effectiveness, the implementation of simple primary interventions is context specific. For example, The Lancet review by Dickson et al. (2014) showed difficulties in implementing Kangaroo Mother Care (KMC) practices in South Asian countries, despite its feasibility in African countries even though they share similar weak health systems characteristics. It indicates that local health care and socio-cultural contexts influence translation of such interventions into reality.

2.4.3 Continuum of Care: An Approach to Reduce Missed Opportunities

Continuum of care has time and space dimensions. Time dimension describes a care approach across a woman's life cycle, particularly around the pre-pregnancy and motherhood-childhood continuum (Mangiaterra et al., 2006; WHO, 2005). The space dimension includes provision of care across family, community to health facility/hospital (Darmstadt et al., 2005; Mason et al., 2014).

Taking an approach to care throughout the life cycle of a woman contributes to perinatal health and survival. Figure 2.2 shows chances for newborn survival begin before the birth and pregnancy. Receiving care along the continuum can prevent millions of deaths and disabilities for mothers, newborns, as well as growing children. Health and nutrition in one stage of life affects health in another life stage, thus resulting in an intergenerational effect (Simon, Rosen, Claeson, Breman, & Tulloch, 2001). The effects of low birth weight and undernutrition can leave lifelong and intergenerational impacts. Evidence shows that in 2012 more than 80% of neonatal deaths in Sub Sahara and South Asia were of small sized babies (both pre-term and small for gestation). If they survive, low birth weight babies and undernourished babies are more likely to suffer disabilities and other chronic non-communicable diseases during their later lives (Lawn et al., 2014), contributing also to the baby girls becoming mothers who are likely to have less than optimal health for successful childbearing.

Figure 2.2 Care along the continuum of pre-pregnancy to postnatal

Source: Adapted from Mangiaterra, Mattero, and Dunkelberg (2006)
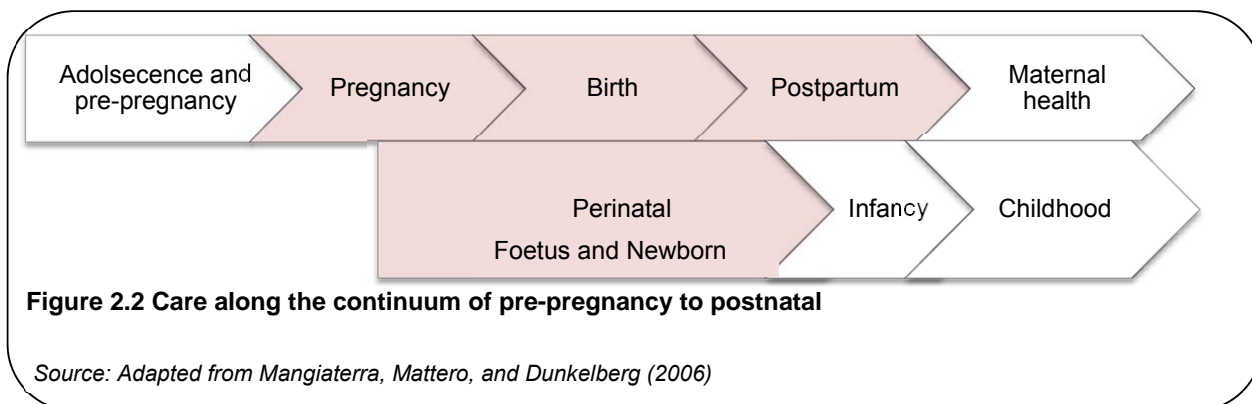
Care across the pre-pregnancy to motherhood-child continuum has been a strongly advised approach after the development of the MDG goals to prevent the previously unnoticed ongoing neonatal deaths (WHO, 2005). The WHO report in 2005 'Make every mother and child count' highlighted this continuum gap—newborn survival falling through the cracks of safe motherhood and child health initiatives.

> …the care of the newborn has fallen through the cracks, as the continuity between maternal and child health programmes is often inadequate. Improving the health of newborns, however, does not just mean inserting a new programme: rather, it means adapting the efforts of maternal and child programmes so as to scale up services in a seamless continuum of care. (WHO, 2005, p. 79)

Implementing interventions across the continuum has been suggested as an effective strategy that takes the benefits of any opportunities to prevent the avoidable deaths in pregnancy, during and after birth (Kerber et al., 2007; Mangiaterra et al., 2006; PMNCH, 2011; WHO, 2005). Evidence already exists that there are available interventions along the pregnancy and postnatal continuum (Bhutta et al., 2005; Lassi, Middleton, Crowther, & Bhutta, 2015; Marsh et al., 2002) and along the continuum of delivery platforms: home/family, community and health facility (Darmstadt et al., 2005; Mason et al., 2014).

With a focus on saving newborn lives, a review of Bhutta et al. (2005) describe a range of essential newborn interventions along the pregnancy to postnatal continuum. This comprised a list of key medical and behavioural interventions (Figure 2.3).

Figure 2.3 Essential newborn interventions along the pregnancy to postnatal continuum

Source: Adapted from Bhutta et al. (2005)
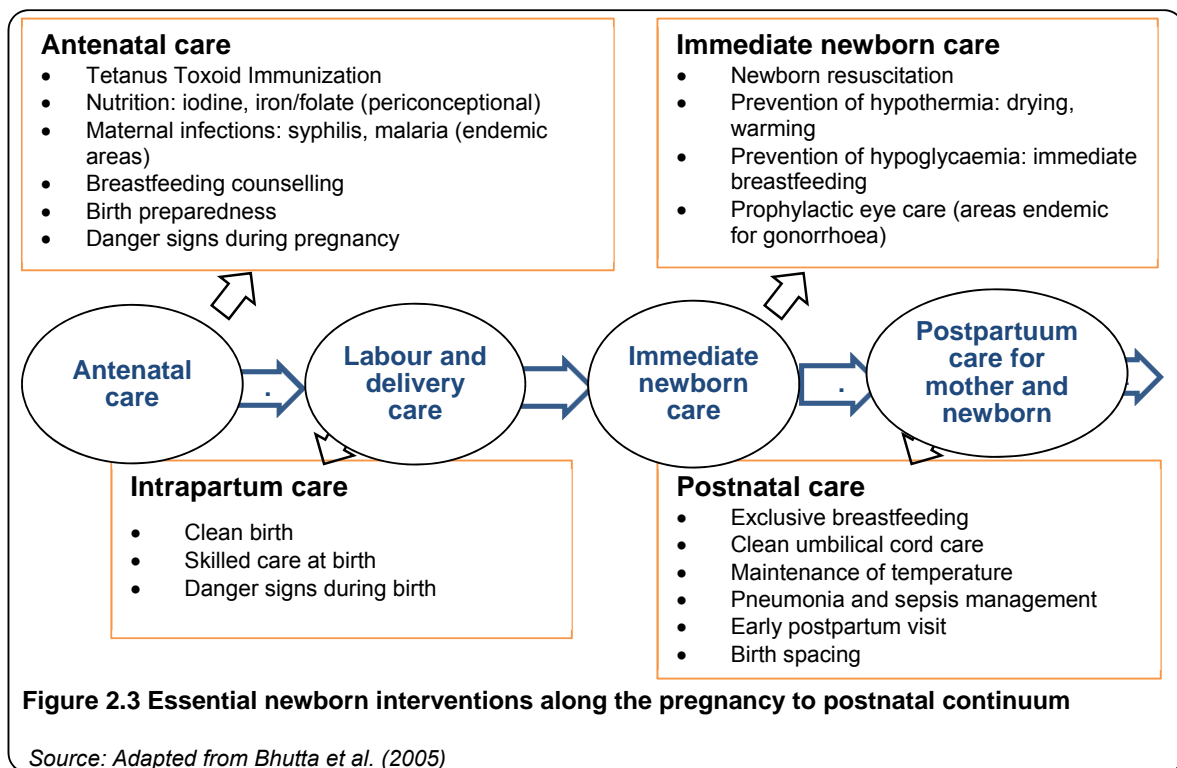
Similarly, along the space dimension, Darmstadt et al. (2005) group the interventions to save newborn lives as follows:

- Facility based clinical care:
  This includes care at a health facility such as skilled maternal and immediate newborn care (attendance of mother and newborn by a Skilled Birth Attendant), emergency obstetric care (such as caesarean section, managing complications such as prolonged labour, retained placenta) and emergency neonatal care (such as resuscitation of asphyxiated baby, care during severe infection, care of very low birth weight babies).

- Outreach care:
  This includes routine population oriented services from health facilities or through community visits such as periodic antenatal care for mothers and postnatal check-up visits for mothers and newborns. Interventions such as immunisation, iron supplementation, deworming, vitamin A distribution, education and counselling women and families about birth preparedness, neonatal care and family planning are parts of these outreach contacts.

- Family-community care:

  This includes home care practices during childbirth and care of a newborn baby; behaviour change communications; community mobilisations and engagement to improve healthy antenatal, birth and postnatal practices; care seeking during mother and baby's illness; and community-based management of newborn sicknesses by community health workers.

It is stated that "…an important aspect of family community care is community mobilisation and the empowerment of individuals and communities to demand quality services that respond to their needs" (Darmstadt et al., 2005, p. 365). The integration of care across family-community, outreach and health facility platforms is more powerful in making positive impacts on perinatal survival than focussing on any one single platform. The integration of activities also facilitates bridging medical and professional space to the social world of families and communities to meet their needs in their local contexts. In this regard, the role of outreach, family-community care is deemed to be crucial. It is considered even more relevant in rural, disadvantaged and poor communities with ongoing high mortality and weak health systems where health care access to every woman and every family is more likely to be compromised.

Continuum of care as an integrated strategy to prevent perinatal deaths

Continuum of care has been an integrated strategy to prevent both stillbirths and neonatal deaths. It integrates maternal and child health strategy, and family-community and health facilities. The available evidence shows that nearly half of the total annual global stillbirths (about 1 million) are babies dying during childbirth, and another half during the third trimester of pregnancy. The interventions around birth prevent both the intra-partum (during birth) stillbirths and the largest proportion of neonatal deaths which occur shortly after birth within the first 24 hours. Interventions to prevent stillbirths also span from pre-pregnancy and continue until childbirth. The purpose of prioritising stillbirth prevention is to expect a healthy newborn child; Frøen et al. (2011, pp. 1,360) state that:

> …the goal of stillbirth prevention is not a live foetus, but a viable infant. It only differs from saving newborn babies' lives in mode and timing of action to provide a continuity of care. Most prevention strategies begin before conception and finish only after pregnancy has ended with a safe birth.

Frøen et al. (2011) discuss that low priority given to stillbirth prevention is a question of ethical value, rights, politics and competing resources. Low value, poorly recognised right to survival of a foetus (conflicting with legal right to terminate pregnancy), poor leadership to bring stillbirths agenda forward, and a low competing priority against maternal and child survival have often undermined stillbirth prevention from becoming a global public health agenda issue. In the last decade, there have been increasing calls for integrating the agendas for preventing stillbirths and neonatal deaths (Table 2.2). These resulted in the formulation of the global Every Newborn Action Plan (ENAP) (WHO, 2014c) which is the first ever global action plan to bring the agenda of

preventing neonatal deaths and stillbirths together. The plan has highlighted that the separation of woman and baby, and family-community and health facility is a false dichotomy. Although the plan gives its main priority to interventions around birth, the framework of action has recognised a continuum along Reproductive, Maternal, Newborn and Child Health (RMNCH) as a key approach to prevent ongoing perinatal deaths in the SDG era.

The ENAP has set a vision to end all preventable perinatal deaths. This plan has cherished the aspirations of millions of women to have healthy babies in pregnancy (foetus) and a healthy newborn.

> The action plan sets out a vision of a world in which there are no preventable deaths of newborns or stillbirths, where every pregnancy is wanted, every birth celebrated and women, babies and children survive, thrive and reach their full potential.

The action plan has framed post-2015 child survival targets with priority given to reduce perinatal death rates to ≤10 for all countries by the end of 2035 (Table 2.3).

Table 2.3 Targets for perinatal mortality and care coverage by 2020, 2025, 2030 and 2035

Year	Neonatal Mortality Rate/1,000 live-births		Stillbirth Rate per 1,000 births		
	National	Global Average	National	Global Average	**Care coverage at National Level**
2020	-	15	-	14	• 90% health facility births receive quality care • 50% Kangaroo Mother Care (KMC) • 50% sepsis management • 20% increase in postnatal care
2025	-	12	-	11	• 95% of all births receive quality care; 90% postnatal care (mother and baby); • 50% exclusive breastfeeding up to 6 months; • >75% Kangaroo Mother Care (KMC); • 75% sepsis management
2030	12	9	12	9	• Achieve SDG Goals
2035	10	7	10	8	• Universal coverage of antenatal, childbirth and postnatal care, KMC, sepsis management

Source: WHO (2014c)

The ENAP targets to reduce perinatal mortality are ambitious. The current global rate of decline for stillbirths (2000 to 2009: 1.3%) and neonatal deaths (2000 to 2012: 2.7%) shows a much slower trend. With the current rates of decline, it is estimated that an accelerated annual reduction of stillbirths (by 3.5%) and neonatal deaths (by 4.5%) is required to reach the targets. Reaching the ENAP's neonatal mortality target is also essential to reach the under-five mortality target. The global initiative called 'Ending Preventable Child and Maternal Deaths: A Promise Renewed' has set an under-five mortality target of ≤20 by 2035. The ENAP also represents the call of the United Nations Secretary-General's Global Strategy for Women's and Children's Health (UN, 2010). The main recommendation of the Secretary-General's strategy is to affirm the RMNCH continuum. The

ENAP has acknowledged the inherent linkage with social determinants, and emphasised the continuum approach to improve perinatal survival (Figure 2.4).

As shown in Figure 2.5, interventions tackling death around birth, such as skilled attendants assisting during labour and immediate newborn care management, have been given specific priority in reducing perinatal deaths. It is argued that interventions around birth are crucial in providing triple returns of actions: reduced stillbirths, reduced neonatal deaths and reduced maternal deaths (WHO, 2014c). The potential of unintended consequences of our non-action in improving care and survival of newborns is estimated to yield a burden of disabilities and morbidities to the millions of babies who survive in the later stages of their lives (Lawn et al., 2014).
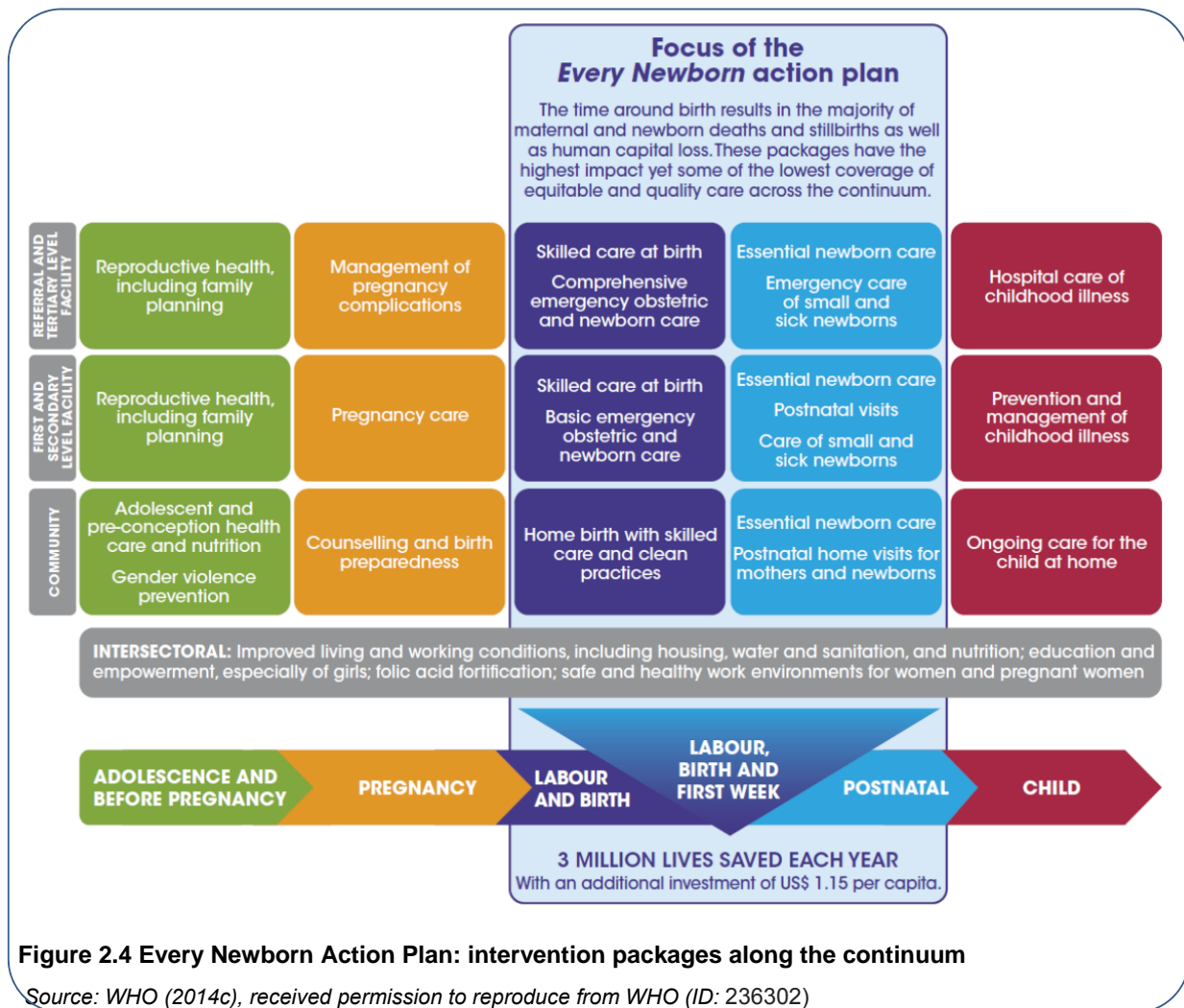
Figure 2.4 Every Newborn Action Plan: intervention packages along the continuum

Source: WHO (2014c), received permission to reproduce from WHO (ID: 236302)

The ENAP has set the following five key strategic activities:

- Strengthen and invest in care during labour, birth and the first day and week of life: considers the time around birth as a critical time.

- Improve the quality of maternal and newborn care: skilled care throughout the continua of pre-pregnancy to postnatal and family-community to health facility.
- Reach every woman and newborn to reduce inequities: considers universal health care and human rights approach as an imperative to reach everyone and reduce inequities.
- Harness the power of parents, families and communities: considers education and empowerment of women and families to generate demand for quality care and home care practices as core essence of this strategic activity.
- Count every newborn through measurement, programme tracking and accountability; every death must be registered and counted.

In summary, basic public health measures and primary health care interventions along the continuum have been found to be effective approaches in improving perinatal survival. This shows that a range of effective public health measures and basic primary health care interventions are still relevant to developing countries and high mortality subregions within these countries. The evidence of success particularly in developing countries such as in South Asia is not uniform. The success is primarily limited to intervention study sites in many South Asian countries except in Sri Lanka, which has achieved universal coverage, and has had a remarkable nationwide success in reducing maternal, neonatal and infant mortality. Universal coverage of health care is still a matter of concern in other South Asian countries. Moreover, prevention of stillbirths has been neither a programme priority in public health, nor a priority research agenda yet. Prevention of stillbirths has often remained divorced from maternal survival, newborn and child survival initiatives. In this regard, the WHO ENAP has brought the prevention of stillbirths and neonatal deaths together as an integrated agenda and set ambitious global and national targets to improve care coverage and reduce mortality. This indicates much remaining work needs to be done in many developing countries and especially in their subregions such as the mountainous region of Nepal, which still has high perinatal mortality rates.

2.5 Socio-cultural and Health Care Contexts of Delivering Care to Mothers and their Newborns

The epidemiology of perinatal deaths is fairly well known. It is also known where such deaths are occurring and with what magnitude (Sections: 2.2, 2.3). Known also are interventions that have been shown to prevent perinatal deaths (Section 2.4). Perinatal deaths continue to occur in various parts of the world, perhaps due to failures of health care systems in delivering the known and proven interventions to appropriate population groups and/or due to hindrances inhibiting the mothers and their families to act according to the known interventions to prevent these deaths. Therefore, attention is now being given to understanding the constraints of the health care system to adapt to local contexts. The priority is to understand the socio-economic, cultural and religious contexts in which health care is being delivered and adapt the delivery system to particular

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contexts so that women and their families from all backgrounds can access the basic provisions of health care in preventing perinatal deaths.

2.5.1 Health Care Systems as a Social Determinant

The health care system is beyond a set of technology based public health and bio-medical interventions. The health or health care system comprises any organisations, people, actions and resources committed to promote, restore or maintain health (WHO, 2000b). The boundary of a health system includes all activities that are primarily intended to improve health. It could be better understood by exploring the WHO's analytical framework to strengthen health systems (WHO, 2007b). According to this framework, a health system comprises six key building blocks: health services; health workers; health information; medical products, vaccines and technology; health financing; leadership and governance (stewardship). Delivery of an intervention is affected by transactions occurring among these different sub-systems. A poor health outcome is not necessarily due to an inherent flaw of any intervention. De Savigny and Adam (2009, p. 21), in a report on 'Systems Thinking for Health Systems Strengthening' comment:

> This is not necessarily due to any inherent flaw in the intervention itself but rather to the often unpredictable behaviour of the system around it. Every intervention, from the simplest to the most complex, has an effect on the overall system, and the overall system has an effect on every intervention.

The health system building blocks are the sub-systems within a health system. Health is produced as an outcome by the interactions of these different sub-systems. Failure in any one sub-system affects another and that ultimately creates obstacles in accessing health services. It is this interaction of the sub-systems which is considered highly context specific—it produces different outcomes in different contexts.

The performance of a health system is measured based on two standards: goodness and fairness (WHO, 2000b). Goodness is achieved if a health system responds well to people's expectations. Likewise, fairness as a standard of health system performance stems from inequities in health outcomes among different population groups. This standard of fairness to access health services makes the health system as a SDH (CSDH, 2008). It is not just about socio-political contexts and social positions, such as socio-cultural beliefs, income level, gender, education level of individuals or a group of a particular population. By the lack of inter-sectoral actions and not being inclusive, accessible and acceptable to certain groups or population in need, the health system itself creates differential exposure to health damaging factors and makes people vulnerable to health damaging conditions. There could be different ways in which people could be excluded from accessing timely and adequate care that vary according to a specific context. The weak and poorly responsible health systems compromise health care access in different ways, such as by differential treatment according to social positions—caste/ethnicity, poverty, gender.

The concept of the health system as a SDH advocates that the current ongoing deaths, disabilities, despair and other poor health outcomes are not just due to lack of interventions, but due to the failure of health systems in addressing the inequities (De Savigny & Adam, 2009). Viewing the health system as a SDH compels health care organisations to be accountable to achieve adequate goodness and fairness in health outcomes. Health outcomes cannot be achieved just by having interventions or technology. Health system as a SDH implies that focus now should be on delivery of available interventions, which requires strengthening of the system to reach everyone with adequate care. The statement of the then director general of WHO, Dr. Margaret Chan, makes it clearer (De Savigny & Adam, 2009, p. 29):

> For the first time, public health has commitment, resources, and powerful interventions. What is missing is this. The power of these interventions is not matched by the power of health systems to deliver them to those in greatest need, on an adequate scale, in time.

Throughout history, health systems have evolved from having no systematic approach until 100 years ago, to vertical disease control approaches during the 1950s and 60s, to the systems which are now expected to ensure universal health care by adopting a comprehensive PHC approach (WHO, 2000b). The concept of a comprehensive PHC approach refers to health systems as a means to ensure universal health care to everyone. Comprehensive PHC emerged as an approach to reaching health care after the social movements which developed during the 1960s and 70s which argued that the difference in health outcomes between haves and have-nots was unfair. This made a shift in value and responsibility of health systems; delivering health care became the key responsibility of governments. Health systems were demanded to be more community-based incurring the key principles of PHC: community participation and empowerment, inter-sectoral action, appropriate technology/mode of delivery that fits the local socio-cultural contexts, and equity and justice—reaching everyone (Walley et al., 2008; WHO, 1978). Primary health care as a part of the health system is considered to be responsible to ensure health care closer to people's homes and communities. Engaging with families and communities, educating, sensitising and mobilising them for preventive and promotion activities remains the priority. As well as preventive and promotive activities, access to basic medical care is ensured, and linked well with referral sites that provide most of the needed medical care. In most countries, including Nepal, the PHC system unit is the district health system comprising a first level referral hospital and a network of PHC centres and health facilities as a link between the community and the referral hospital (WHO, 2007b).

Recently, studies analysing health system barriers in essential newborn interventions have also included 'community ownership' as an additional component within the WHO framework (Dickson et al., 2015; Dickson et al., 2014). The WHO framework includes six key elements: human resource, health service, finance, information, medicine/technology and logistics, which are mostly the supply side inputs (WHO, 2007b). Addition of community ownership and empowerment as an

additional element recognises a vital role of communities in shaping their health status. Sociologists and anthropologists have viewed health, illness and recovery as socio-cultural concepts and the health system as a socio-cultural system. Kleinman (1978) describes that perception of illness occurs first within a family/domiciliary context. Responses to illness, first involve self-care or self-treatment, and care within family and the network of extended family. Care is then usually sought from traditional/faith healers, or from other locally available healers outside the formal health care system. It is noted that 70 to 90% of self-recognised sickness episodes are treated outside the formal health care system, thus covering a large proportion of sickness management. In this regard, Kleinman (1978) expands on the concept of the health system beyond the commonly assumed formal health care facilities—the professional arena. The health system is expanded to include the popular/folk arena and family/domiciliary arenas that cover socio-cultural beliefs and values about health and health care, such as traditional healing, and recognition and response to illness within a family.

Health system barriers and perinatal survival

As discussed above, a functioning health care system enables the implementation of interventions and ensures access to quality health care to everyone, especially to those in the greatest need. As presented in the previous sections, over time the policy and research on perinatal survival have increasingly highlighted the crucial role of the health care delivery system. Intervention beyond bio-medical that includes a broader health system approach is crucial to accelerate the progress in reducing perinatal deaths. It is noted that in many Sub Saharan and South Asian countries, the slow trend in neonatal mortality reduction over the last two decades is due to weak national and sub-national health care systems that could not address coverage gaps and constrained the implementation of the available interventions (Darmstadt et al., 2014; Frøen et al., 2016). Section 2.5, literature has provided evidence that effective interventions are available to reduce neonatal deaths (Bhutta et al., 2005; Bhutta et al., 2014; Darmstadt et al., 2005; Lassi & Bhutta, 2015) and stillbirths (Bhutta et al., 2014; Bhutta et al., 2011; de Bernis et al., 2016). However, contextual barriers in health service delivery have been crucial for a timely and effective delivery of the interventions. Some of these barriers are related to the role of health systems in ensuring accessible and acceptable care; behaviour of health providers, workforce availability and support, and reporting systems, which are discussed below.

Equitable access to acceptable and high quality care

The poor socio-economic situations of families, communities and countries adversely affect the uptake of quality reproductive care including pregnancy, childbirth and postnatal services (Filippi et al., 2006; Greene & Merrick, 2005; Kyomuhendo, 2003; Thaddeus & Maine, 1994). Access to quality care is further aggravated in remote and rural subregions of developing countries where the poor socio-cultural factors and constraints of the weak health systems often interact to impact on

health and survival of mothers and children (Darmstadt et al., 2005; Dickson et al., 2014; WHO, 2014c). Studies from developing countries have found that the local health care system has excluded certain groups of the population from accessing and accepting the available care (Bazzano, Kirkwood, Tawiah-Agyemang, Owusu-Agyei, & Adongo, 2008; Goulart, Somarriba, & Xavier, 2005; Samuelsen, Tersbøl, & Mbuyita, 2013). Health service factors can shape how a particular group of people experience care, which in turn can influence their care seeking behaviour either positively or negatively. A study from Tanzania found that disadvantaged population groups were given low priority by health providers in relation to maternal and child care (Samuelsen et al., 2013). This study reported dissatisfaction among women from low socio-economic groups on the care they received concerning infant disease management. Other issues limiting access to health services included payment issues in relation to the treatment of sick children in health facilities, ineffective referral systems—sick children often referred to someone without medical expertise, and inefficient organisation of health services that required women to go through several points within a health facility before treatment started. The study found that despite a cost exemption policy for treatment and consultation of all under-five children in Tanzania, parents often had to pay for their children's treatment. The costs were unpredictable, and treatment started only when they had paid—thus causing a delay in receiving timely treatment in health facilities. The authors argued that the poorest segments of the population were the most affected by such constraints. Similarly a study in Brazil identified that mothers reported referral complexities during their infants' illness and poor communication of information by health service providers (Goulart et al., 2005). The women were required to go from one hospital to another during their infants' sickness, which delayed receiving timely care and resulted in deaths of a number of children.

Service providers' behaviour

It is clear that health providers' poor behaviour has compromised women's access to health care in many developing countries. Several studies have found that mistreatment by health providers is a key factor in preventing women from accessing care during childbirth and during their baby's fatal illness (Andajani-Sutjahjo & Manderson, 2004; Dhingra et al., 2014; Goulart et al., 2005). In some cases, health provider behaviour acted as a single predominant factor (McMahon et al., 2014; Sutrisna et al., 1993) whereas, in other cases, along with other contextual factors, provider behaviour remained a significant factor in making women reluctant about seeking health care (Dhingra et al., 2014; Kumbani, Bjune, Chirwa, & Odland, 2013; Morrison et al., 2014). In Indonesia, studies found mothers' previous negative experience with health facilities as a key barrier in seeking care during their children's fatal illness, while the physical distance between home and health facilities, maternal age, education and household income were not found to be associated with care seeking (Andajani-Sutjahjo & Manderson, 2004; Sutrisna et al., 1993). In Laos, ill treatment by health workers, along with high cost of the care and transportation difficulties,

negatively impacted on women accessing care (Dhingra et al., 2014). Similar findings were also reported in a hilly eastern district of Nepal (Morrison et al., 2014). In addition to transportation and financial difficulties, women decide not to attend health facility births due to their past negative experiences in health facilities and embarrassment by the service providers. In Malawi, for example, the attitude of health workers was identified as a significant barrier to attending a health facility for childbirth with women experiencing shouting and rude behaviour from health workers (Kumbani et al., 2013). Women were found to be less reluctant to seek care when labour started at night and during the rainy season. In Tanzania, McMahon et al. (2014) identified that women felt ignored, verbally abused, neglected and experienced discriminatory treatment. It was seen that men and women had no easy way to either accept such behaviour or ignore care seeking. Some males were found to bribe and pay for better care, but women were found to adopt strategies such as accepting the abuse, returning home or bypassing one health facility for another. Similar negative experiences were reported by women attending local maternal and child health clinics in rural Ghana (Bazzano et al., 2008).

Service recipients' behaviour related to construction of perinatal deaths as the results of supernatural forces are described in Section 2.5.2 under *'Socio-cultural Constructions about Perinatal Deaths'*.

Workforce availability and support system

Availability of Skilled Birth Attendants (SBAs) is associated with reduced maternal and neonatal mortality rates. However, millions of women continue to give birth at home without skilled service providers. As discussed in Section 2.5, the well-organised midwives programmes in a developed country such as Sweden (Andersson et al., 2000; Hogberg, 2004) and also in a developing country such as Sri Lanka (Caldwell, 1986; Pathmanathan & Liljestrand, 2003) have demonstrated significant improvements in maternal, neonatal and child survival. However, despite national policies talking about retention of staff, and 24-hour access to skilled birth and obstetric emergencies, this has continued to be a key challenge in developing countries. The problem could be due to insufficient numbers of health service providers but in some cases, it is due to service providers' lack of responsibility. As reported by some women in a Nigerian study, there were no staff present during the night (Exley et al., 2016) and consequently the women ended up giving birth at home without skilled attendants. Service providers' absence from health facilities is in turn due to their demotivation, poor recognition and lack of value within the health system (Haines et al., 2007; Maclean, 2003). An enabling environment and support for health providers is therefore essential to provide care to every women and child especially in the rural communities. However, the solution to this dilemma appears to be context specific. Some countries have initiatives, such as task-shifting, to increase access by encouraging service providers, for example in countries such as Malawi, Mozambique and Tanzania, non-physician clinical officers conduct caesarean sections (Kinney et al., 2010). Nepal has introduced a service provider incentive for a skilled

provider to attend women at health facilities (MOHP, 2013). The service provider receives a monitory incentive per childbirth attended in health facilities. Likewise, policies in Nepal also state that SBAs in rural areas receive strong support from the local health facility team, from the district health office, and receive accommodation in health facilities (MOHP, 2006a, 2006b).

Several countries have introduced a community health workers approach for basic maternal and newborn care activities in the communities—Extension Health Workers in Ethiopia (Koblinsky et al., 2010), and Community Health Workers (CHWs) in South Asian countries (UNICEF, 2004). In Bangladesh, India and Nepal, CHWs are involved in assessing, counselling, treatment, and referral of newborns and under-five children with common health problems (UNICEF, 2004). Nepal's FCHVs are considered pillars of community health (New ERA, 2007). Their role is to mobilise women's groups called 'Mothers Groups', follow-up mothers and their newborns in home visits, and educate, counsel and link them to health facilities if required during sickness.

Reporting system

Underreporting is a major health system issue in many developing countries with regard to perinatal deaths. Poor recording and reporting of perinatal deaths is mainly due to the low priority given to the prevention of perinatal death within health systems (Frøen et al., 2011; Lawn et al., 2005). Millions of babies continue to die before their first birthday without a birth certificate. Globally, it is estimated that 48.5 million births are not registered by their first birthday, nearly half of them are in South Asia (Lawn et al., 2014). Birth or death certificates for a stillborn baby are rarely issued. Until recently, many countries did not prioritise health care for preventing perinatal deaths (WHO, 2014c). Instead, the focus remained mainly on the post-neonatal infants and under-five children. In some instances, the actual magnitude of the problem has been under stated, and a large gap exists between officially reported statistics and actual status. For example, in one province of Vietnam, where the neonatal mortality was recorded as four (per 1,000 livebirths) in the official records, according to a study by Målqvist et al. (2008), this was actually 16 (per 1,000 livebirths). There are also some false beliefs that reporting neonatal deaths reflects badly on the performance of health workers (Bang, Reddy, & Deshmukh, 2002).

It is seen that different health system factors constrain access to care, such as those related to the role of health providers or the local health system, behaviour of health providers, issues about workforce availability and support, and reporting affected by whether or not perinatal survival is a health system priority. It is also known that such factors are highly contextual. Understanding these factors is crucial in every health system because having known interventions, and a concern for equity in perinatal survival as discussed, now is the time to ensure whether even basic care is reaching every mother and every newborn.

2.5.2 Socio-cultural Views on Preventing Perinatal Deaths

The above section described different aspects of health systems impacting on delivery of care to mother and newborn's survival. This section begins with describing the growing importance and evidence on SDH. An overview of commonly used maternal and child survival models/frameworks, which are relevant to perinatal survival in developing countries, reveals a growing body of evidence on the importance of a socio-cultural focus. The section then explores broader social determinants related to perinatal survival, the socio-cultural contexts of the major causes of perinatal deaths, and the cultural constructions of these deaths.

Social determinants of health: importance and growing evidence

The importance of a socio-cultural approach in health traces back to the WHO's vision for health as 'social and spiritual well-being, not merely as the absence of disease or infirmity' (WHO, 2014a, p. 1). Health is understood as a dynamic process influenced by the interactions of social, psychological, spiritual and biological factors. A social model of health is the core of the comprehensive PHC approach (WHO, 1978). This has been supported by international declarations such as the Ottawa Charter for Health Promotion, and has been further reaffirmed by the WHO Commission on Social Determinants of Health (CSDH, 2008) and the UN post-2015 SDG framework (WHO, 2015a). The CSDH views health as an outcome of socio-economic, political and cultural contexts that define individuals' social positions such as occupation, gender, and ethnicity. This view eventually leads individuals to differential exposures to vulnerabilities. Socio-economic and cultural conditions in individuals' day to day living situations where they are born, grow, work and age, provide settings in which the influences and interrelations of socio-economic, cultural and political contexts and social positions can be studied.

A socio-cultural approach is the foundation of good public health. Baum (2016) discusses new public health going beyond the bio-medical approach and a single discipline. To address inequities in health outcomes, concepts such as culture, economy, justice and power are emerging interests in a new public health approach. Baum discusses new public health as an inter-disciplinary approach to tackle complex problems by understanding the relationships and influences of structural determinants such as gender and power. Likewise, Labonte (1992) discusses a socio-environmental approach that considers mobilising and empowering communities to take control over their health matters. Labonte's socio-environmental approach is a community development approach that argues for empowering communities to set their priorities and decisions for improving health. Labonte views health as a resource created in interconnected relationships of an individual with families, friends and communities; and problems as psychosocial and environmental risk conditions. Labonte, Mohindra, and Schrecker (2011) reinforce that research, policy and practices in public health should focus on SDH to reduce existing gaps and inequities.

Socio-cultural focus: central to frameworks/models related to maternal and child survival

This section gives an overview of key analytical frameworks and concepts used in maternal and child survival and their main focus (socio-cultural, bio-medical/behavioural). These frameworks are also argued as being relevant to guide interventions and studies about perinatal survival in developing countries (Table 2.4).

Table 2.4 Models/framework used in maternal and child survival related research (also relevant to perinatal survival)

Model/Framework /Concept	Key Argument/Approach	Main Focus (Medical, Behavioural, Socio-cultural)
Analytical framework of the determinants of child survival, Mosley and Chen (1984)	• An integrated analytical model of social and medical science approach to child survival • Emphasis on socio-economic, environmental and biological forces influencing child survival • Socio-economic factors operate through a set of five categories: (i) maternal factors (e.g. age, parity, birth interval); (ii) environmental contamination (various routes of spread of infection/diseases); (iii) nutrient deficiency (food consumption, specific deficiency in mother or child); (iv) injury (intentional such as infanticide, and accidental); and (v) personal illness control measures (preventive measures to protect health and medical treatment during sickness) • Socio-economic determinants at three levels: (i) Individual level, such as individuals' education, occupation, norms, values and beliefs, value of children; (ii) home/family level, such as housing, sickness care, transportation; and (iii) community level, such as health systems related factors	• **Focus on socio-cultural, behavioural as well as medical aspects** • Primarily used to study factors behind under-five child mortality • Emphasises that "…child mortality should be studied more as a chronic disease process with multifactorial origins than as an acute, single-cause phenomenon" (Mosley & Chen, 1984, p. 41) • Does not consider stillbirth as an outcome, focuses on survival of under-five children • Understanding of the links between socio-economic determinants and proximate determinants can provide useful insight for policy makers that could be relevant to contribute to improve perinatal survival
Framework for analysing the determinants of maternal mortality, McCarthy and Maine (1992)	• An integrated framework for analysing the cultural, social, economic, behavioural and biological factors of maternal mortality • All determinants of maternal mortality operate through sequence of three intermediate outcomes: (i) likelihood of pregnancy (conception); (ii) likelihood of pregnancy and birth complications; and (iii) treatment outcome of the complications • The intermediate outcomes are influenced by five sets of intermediate factors: woman's health status; reproductive status such as age, parity, birth interval; access to health care (location, quality, range of family planning, pregnancy, childbirth services); health care behaviour (including use); and unknown factors • Background factors at the deepest roots called distant determinants, such as socio-economic and cultural factors related to women's status within family, family's status in community, and community resources such as health workers, health facilities	• **Focus on socio-cultural, behavioural as well as medical aspects** • It can be argued that preventing the likelihood of pregnancy and obstetric complications can help to prevent stillbirths and neonatal deaths
Three delays	• A commonly used conceptual framework to identify and analyse factors	• **Focus on socio-cultural aspects causing delays to**

model, Thaddeus and Maine (1994)	• Emphasis on addressing the delays from the onset of pregnancy and birth complications. The delays include: (i) Delays in deciding to seek medical care (socio-cultural factors); (ii) Delays in reaching health facility (accessibility to health facility); and (iii) Delays in receiving care in health facilities (quality of care)	**health care seeking** • Primarily a maternal survival model developed to examine maternal deaths and facilitate timely treatment of obstetric complications • Still, it can help to prevent stillbirths and neonatal deaths by preventing delays in seeking health care during pregnancy and birth complications. • Used to describe a pattern of delays causing perinatal deaths (Alvesson, Lindelow, Khanthaphat, & Laflamme, 2012; Kidanto et al., 2009; Upadhyay, Rai, & Krishnan, 2012; Waiswa, Kallander, Peterson, Tomson, & Pariyo, 2010) • The influences and inter-relationships of socio-cultural factors (first delay), accessibility to health facilities (second delay), and quality of care (third delay) can provide a detail context which can help to improve both maternal and perinatal survival.
Pathway to child survival model, CDC and USAID (1996)	• A model to deliver care for sick children • It is believed that most of the care for a sick child occurs outside a health facility • Recommends giving attention at the critical points: (i) Inside home for a care provider so that s/he recognises a problem, provides quality care, and seeks care from a health facility; (ii) At health facility to skill a health worker to provide quality care and to refer the case as needed; and (iii) Follow up care and compliance by caregiver	• **Focus on medical and health behaviour** • Developed to contribute to the goal of integrated management of childhood illness (IMCI). Until 1980s, there were separate vertical disease control programmes, such as control of diarrhoeal disease, respiratory infection, malaria, measles vaccination • Emphasis on the integrated service delivery for sick children who are less than five years, the role of carers, service providers and health system such as supplies • This can also help to prepare carer and health facilities to save lives of newborns although the model does not specifically talk about newborn

Advancing newborn pathway to survival model, Marsh et al. (2002)	• A framework to advance household and community newborn and maternal survival • Identifies five pathways to improve maternal and newborn survival: (i) Use of routine maternal and newborn services; (ii) Response to maternal danger signs; (iii) Response to non-breathing newborns; (iv) Care for low birth weight babies; and (v) Response to newborn danger signs (especially infection) • Mother and baby as an integrated continuum, and therefore presents care in pregnancy and postnatal continuum as crucial to advance newborn survival • A specific focus to advance neonatal survival in developing countries	• **Focus on correcting health behaviour** • The model seems prescriptive with routine and special practices related to danger signs in pregnancy, labour/birth, newborn danger signs, asphyxia and low birth weight • Emphasises 19 routine behaviours/practices, danger signs along the pregnancy to postnatal continuum • Although it is a framework developed to improve care at household and community level, socio-cultural factors surrounding stillbirths and neonatal deaths are not the subjects of discussion in the framework
Verbal autopsy	• Involves interview with a primary care giver of the deceased (Baiden et al., 2007; Leitao et al., 2013); • Physician based reviews (medical history, standard algorithmic methods) (Fottrell & Byass, 2010); and • Quantifies causes or causal categories	• **Focus on identifying medical causes of deaths** • Does not capture socio-cultural aspects; arguments have been made to move towards programmatically important causes of deaths (multiple causes to one category rather than one cause to one death) (Fottrell & Byass, 2010)
Death audits or death reviews, and near-miss reviews	• Used mainly as quality of care tools to address avoidable factors contributing to perinatal deaths • Involves a review of perinatal deaths (Kerber et al., 2015; Pattinson et al., 2009), or near-death cases (events) at health facilities (Santos et al., 2015; WHO, 2011b); • Audit process is cyclical, includes identification of case (perinatal death), collection of information on causes/avoidable factors, analysis (rates, trends over time), and identification of solutions, implementation, evaluation and ongoing review (Pattinson et al., 2009); and • The audit or review occurs within audit/review committee that comprises health workers, health facility management stakeholders, and family representatives • Predominantly a quantitative analysis	• **Focus on medical and administrative aspects in health facilities** • Targeted mainly to identify medical and programmatically avoidable factors behind deaths and near-miss conditions of mothers and newborns at health facilities
Social Autopsy	• An approach emerging mainly with the interest to complement verbal autopsy (Biswas & Rahman, 2016; Kallander et al., 2011; Pattinson et al., 2009; Waiswa, Kalter, Jakob, & Black, 2012); and • Combines both quantitative analysis, and includes death narratives as well as medical causes/causal categorisation	• **Introduced to complement verbal autopsies by adding socio-cultural aspects** • Identifies modifiable social, behavioural and health system factors that constrain or delay care seeking • Aims to identify factors related to care seeking during fatal illness

Many of the above models (Table 2.4) are aimed at understanding or addressing bio-medical needs when a woman or a child becomes sick. Yet, some have gone beyond, and have also talked about broader socio-cultural determinants of maternal and child survival. None of the models have denied the importance of socio-cultural aspects, which became explicit when arguments grew to complement verbal autopsies with social autopsies. It is evident that frameworks by Mosley and Chen (1984), McCarthy and Maine (1992), and Thaddeus and Maine (1994) have strongly recognised the importance of understanding and addressing socio-cultural determinants. Although the Three Delays Model (Thaddeus and Maine, 1994) is essentially a maternal survival model, it is argued that the timely provision of emergency obstetric care to women in their late pregnancy can save the lives of not only the women but also of the babies. It can prevent intra-partum stillbirths and neonatal deaths, as evidence in Section 2.4 showed that globally nearly half of these deaths are related to obstetric complications, and the proportion is likely to be even higher in some developing countries due to the lack of 24-hour access to obstetric care. The model developed by McCarthy and Maine (1992) is also a maternal survival model. However, it is argued that preventing the likelihood of unintended conceptions (family planning), complications (vulnerabilities), and treatment (timely care seeking if obstetric complications occur), can prevent occurrences of stillbirths and save the lives of thousands of newborn babies. The pathway to child survival model (Waldman, 1996) and the advancing newborn pathway to survival model (Marsh et al., 2002) have recognised the need to address home/family-community environments to improve health behaviours and to ensure appropriate health care for sick children. Verbal autopsy is aimed at identifying bio-medical causes (Baiden et al., 2007; Leitao et al., 2013); therefore, argument has been made to complement it by social autopsy (Biswas & Rahman, 2016; Kallander et al., 2011; Pattinson et al., 2009; Waiswa et al., 2012). Social autopsy adds death narratives, the stories that reveal socio-cultural aspects behind perinatal deaths, whereas death audits, death reviews (Kerber et al., 2015; Pattinson et al., 2009) and near-miss reviews (Santos et al., 2015; WHO, 2011b) have a programmatic purpose that mainly targets correction of constraints in the health facility environment.

The above models provide flexibility to direct research in any directions: socio-cultural as well as public health and medical view. These provide a good ground, or scope for a range of content areas to be focused on inquiring about maternal and child survival. Still, in applying them, as a researcher with socio-cultural focus, a caution is needed to minimise the swamping of bio-medical intentions and influences that can take a researcher away from putting a purely socio-cultural approach. In this regard, it can be argued that use of these models should be carefully chosen in qualitative research so that a researcher can still exercise flexibility and openness in a study.

Socio-cultural constructions about perinatal deaths

Pregnancy, childbirth and pregnancy outcomes are commonly linked with religio-cultural beliefs and values (Degefie et al., 2014; Kain, 2014; Naidu, 2014; Rice, 2000a; Shaw, 2014). Some factors contributing to high perinatal mortality in developing countries are the acceptance of death and stigma that leads to the invisibility of the ongoing perinatal deaths (Dickson et al., 2014; Ghosh, 2012; Lawn et al., 2014; Målqvist et al., 2011; Rusman, Djohan, & Hill, 1999). Perceptions of perinatal deaths as non-significant events, and the existence of a fatalistic view and stigma have been shown in studies conducted in African (Degefie et al., 2014; Haws et al., 2010), Asian (Aggarwal et al., 2003; Rusman et al., 1999) and migrant Australian communities (Rice, 2000a, 2000b). The Hmong women living in Australia believed that disharmony in personal health, as well as in the supernatural world, causes miscarriage, stillbirths and neonatal deaths (Rice, 2000a, 2000b). The perinatal deaths were considered non-significant events, not even requiring a burial ceremony (Rice, 2000a). Studies from Ethiopia, Tanzania, Uganda and Ghana found similar perceptions of women and their families about neonatal and infant deaths. In Ethiopia, dead babies (stillborn) were often buried in the house or in the backyard; supernatural powers were perceived to cause perinatal deaths (Degefie et al., 2014). Mourning perinatal deaths was not permitted. These were considered to be according to God's will and therefore mourning such deaths was believed to be an act against God's will. In a northern district of Ghana, a study by Denham, Adongo, Freydberg, and Hodgson (2010) identified up to 2% of neonatal deaths were rationalised as being due to spirits from bushes, called 'spirit child'. In Uganda stillbirths are viewed as of low concern '*empuna*' and '*ekintu'* reported *as* a 'thing'(Kiguli, Namusoko, Kerber, Peterson, & Waiswa, 2015). Such deaths were not perceived to require organisation of a cultural burial practice, and were left up to women to deal with. In particular, with antepartum stillbirths, women and families were often stigmatised.

Fatalistic beliefs and perceptions have influenced the reporting of perinatal deaths. In developing countries, the already poor tracking of perinatal deaths due to weak vital statistics and poor reporting through health systems, suffers even more due to the fatalistic beliefs and perceptions around perinatal death. As already stated, globally, a large number of newborns continue to die without a death certificate, and millions do not get birth certificates until their first birthday (Lawn et al., 2014). When live-born babies are not counted, counting stillbirths becomes an even lower priority across the world. Based on health care professionals' perceptions about stillbirths through a web-based survey, a study identified that four out of every five stillborn babies were not given a name (Frøen et al., 2011). They were simply disposed of without a name and without ritually recognising the need for a funeral. The survey showed that one-third of stillbirths were commonly attributed to the sin of the mother, evil spirits, and natural selection—that the stillborn babies were never meant to live. Health professionals from 138 different countries around the world, and parents in high income countries, participated in the study, and they were expected to represent

their communities' beliefs and perceptions. The study found that even in high income countries such as Australia, 63% of parents and 30% of health professionals believed that stillbirth is a result of natural selection. Of the parents and health professionals participating from five high income countries (Australia, Italy, Norway, UK, USA), the lowest proportion of parents (21%) and health professionals (10%) who responded that the occurrence of stillbirths was natural selection were from Norway. These responses clearly indicate that fatalism about stillbirth is widespread among parents and health professionals.

Major causes of perinatal deaths mediated by socio-cultural contexts

It is evident from the evidence in Table 2.2 that infection, complications of prematurity (low birth weight or small for gestation) and birth related complications such as prolonged or obstructed labour and birth asphyxia are the major causes of ongoing perinatal deaths. Complications of prematurity and birth are major causes of stillbirths. Birth complications are reported to cause approximately half of the global stillbirths that occur during birth, almost all in developing countries; of which nearly two-thirds occur in rural areas (Lawn et al., 2016).

Interactions among a range of social, behavioural and medical factors affect the care process and compromise the baby's health and survival (Mosley & Chen, 1984; Waldman, 1996). In a real field situation, rather than a single cause or a causal category, a series of sequential pathways eventually lead to the death of a child. For example, babies born pre-term are more susceptible to infection, which can eventually prove fatal. Infection occurs due to poor socio-environmental conditions. Single cause or causal categorisation can therefore undermine the effects of socio-environmental factors. Severe infection constitutes up to half of the total neonatal deaths in countries with a very high mortality rate (neonatal mortality rate=45 or more), and mostly these are the low income countries with poorly functioning health care systems (Lawn et al., 2005). By comparison, infection constitutes only about one-fifth of the total deaths in high income countries (neonatal mortality rate=15 or lower). The risk of death due to infection is 11 times higher in high-mortality countries compared with the risk in low mortality countries (Lawn et al., 2005). Poor living conditions, poor hygiene and lack of sanitation contribute to the high proportion of infections in high mortality countries (Lawn et al., 2005). Adequacy and quality of water, and sanitation measures in households are associated with infections, commonly diarrhoea. In developing countries, diarrhoea and pneumonia are the most common infections in newborns and older infants. In addition, poor quality homebirths without skilled attendants are major sources of infection in South Asian countries. In Nepal, a recent national level community verbal autopsy found that nearly half of neonatal deaths (48%) occurred due to infection (Dhakwa et al., 2014). Newborns dying due to infection in the rural population and the mountainous regions of Nepal are likely to be higher due to a large number of ongoing homebirths without the assistance of skilled attendants, lack of running water supply inside the houses, and poor hand washing practices in the rural areas. Less than half of the households in Nepal have adequate sanitation (having latrines), and over one-third of the

households need to walk more than 15 minutes to fetch water (Government of Nepal, 2016). In the rural areas, it is very likely that the majority of households have no water tap inside their houses.

Similarly, low birth weight is a major contributor to neonatal deaths. In high burden countries, up to 80% of neonatal deaths occur among small sized and sick newborns (WHO, 2014c). Babies weighing less than 2.5 kilograms are described as low birth weight (LBW) babies. Low birth weight babies are more susceptible to neonatal deaths (McCormick, 1985). They are highly susceptible to hypothermia, which eventually perpetuates infection and death. Low birth weight could be the result of prematurity (birth before 37 weeks) or Intra Uterine Growth Restriction (IUGR) or both (Lawn et al., 2005). According to the UNICEF (2014) State of the World's Children report, 15% of babies in the world are born LBW. In South Asia the burden is the highest--with over a quarter (28%) of LBW babies. Women from poor and socially disadvantaged classes are more likely to have LBW babies (WHO, 2003a, 2003b). WHO (2003b) argues that chronic poverty often leads to malnutrition and poor nutritional status, and the social stigma surrounding a disadvantaged class which creates chronic stresses, ultimately induces physiological impacts contributing to the pregnancy complications, poor growth of the baby in uterus, premature birth and LBW. Premature birth is often a cause of LBW, and it is also argued that psychosocial factors such as maternal anxiety and stress during pregnancy also induce pre-term birth (Dolatian et al., 2012).

Women's health and nutritional status during their childhood, adolescence and pregnancy is associated with increasing vulnerability to problems, such as LBW, infection, and poor foetal and neonatal survival (WHO and UNICEF, 2013). Women's poor nutrition during pregnancy contributes to the poor growth of foetus in uterus, and thereby to the poor perinatal outcomes (Imdad & Bhutta, 2011, 2012). Maternal malnutrition is also associated with poor cognitive growth and development. As evident from a US study, pregnant women with low frequency intake of food were found more likely to have a premature birth (Siega-Riz, Herrmann, Savitz, & Thorp, 2001). The type of food, its amount and frequency determines nutrition intake during pregnancy which in turn is associated with the child's health and survival. The ability to ensure adequate food and nutrition during adolescence, pregnancy and the postnatal period is affected by several factors such as household food security, gender and cultural norms and taboos during menstruation, pregnancy and the postnatal period (Njikam, 1994; Raj et al., 2011).

Likewise, socio-cultural factors worsen the consequences of pregnancy and birth complications in developing countries. The argument of the well-known three delays model is to prevent delay in treatment of pregnancy and obstetric complications to prevent avoidable maternal mortality (Thaddeus & Maine, 1994). Timely care seeking during pregnancy and birth complications not only saves mothers, it also saves babies in pregnancy (foetus) as well as during childbirth (WHO, 2014c). Therefore, skilled attendants' assistance during birth has been a key focus of global and national policies to prevent maternal deaths, stillbirths and neonatal deaths. Delay in the decision

to seek care occurs due to socio-cultural factors related to the recognition of danger signs, perception and interpretation of pregnancy and birth complications on the part of women and their families. It then prevents women from accessing timely and appropriate health care during any complications. Socio-cultural interpretation of pregnancy threats leads women to seek care from different sources, such as traditional birth attendants, herbalists, or faith healers in Ghana, thus causing a delay in seeking appropriate care after any complications (Dako-Gyeke, Aikins, Aryeetey, Mccough, & Adongo, 2013). A mother must wait to deliver at home until a specific prayer time in Muslim prayers (Cham, Sundby, & Vangen, 2005), or she is persuaded to progress her labour by using certain herbs believed to flex the pelvic bones for quick and safe childbirth in Gambia (Jammeh, Sundby, & Vangen, 2011). Already sick pregnant women wait to have a response from prayers, holy water, abdominal massage and traditional therapies in Ethiopia (Berhan & Berhan, 2014). Eclampsia and postpartum haemorrhage are interpreted as being due to the will of God *(Allah)* and evil spirits in Bangladesh (Kalim et al., 2009). Eclampsia is perceived as a 'devil disease' that does not require hospital treatment in Ethiopia (Berhan & Berhan, 2014). Bleeding is seen as a normal transition after birth; blood passing after birth is considered to be having bad blood washed out to make the woman pure in rural Nepal (Matsuyama & Moji, 2008). Thus, such socio-cultural interpretation of obstetric complications delay women's timely treatment, and also reduce the chances of saving a baby in pregnancy (foetus) and a newborn during the critical first few hours after birth. In low-income countries, newborns are likely to be left unattended when increased attention is given to restore the mother's health due to complications.

Broader social determinants and perinatal survival

There has been a growing realisation of the need to address broader social determinants in reducing perinatal deaths. Reducing ongoing deaths of mothers, newborns and children requires addressing 'causes of the causes'; it is stated that "no discussion of global maternal, newborn, and child health is complete without addressing basic issues of social determinants" (Bhutta & Black, 2013, p. 2229). Health inequity is evident in perinatal deaths with people living in the rural, marginalised, urban slum and conflict affected regions in developing countries who suffer more from poor health conditions and mortality outcomes.

Place of birth, poverty

Broad ranges of social determinants contribute to inequity in perinatal health. There is a striking difference in magnitude of perinatal deaths between developed and developing countries (Section 2.2, Table 2.1). This is also evident by the neonatal mortality difference between the well off and the poor families in developing countries (Lawn et al., 2014). A study by Luo et al. (2004) in Canada showed persistently high perinatal mortality rates among the poorest 20% of the population. Similarly, as per 2012 mortality data, a review estimated a likely reduction in neonatal mortality by 48% in Cambodia, 46% in Nepal, and 41% in India and the Philippines from their 2012

level which was associated with a reduction in income inequalities in these countries (Lawn et al., 2014). The same study further estimated that if the bottom 20% of the world population experienced the level of risk similar to that of the top 20%, it would have saved the lives of an additional 600,000 newborns in 2012 alone. Although there is no separate estimation about likely reduction in stillbirths, it might have saved a large number of stillborn babies as well. Globally, evidence shows that nearly 65% of stillbirths occur among women with adverse socio-economic status, and mostly among those who are living in rural areas of developing countries (Lawn et al., 2016). The proportion of stillbirths occurring among rural families is even higher (>70%) in Sub Saharan and South Asian countries. Even in high income countries, it is found that women from adverse socio-economic situations are at more than twice the risk of having a stillborn baby (Flenady et al., 2016).

Socio-demographic determinants

Studies have shown a range of social determinants such as education, income, employment, social status, living conditions, and the health care contexts impacting on newborn survival (Mahy, 2003; MOHP et al., 2012; Paudel et al., 2013b). Women's education and occupation are the key influences on the health care they access during pregnancy and birth. For example, a large scale multi-country (56 developing countries) analysis of Demographic and Health Survey (DHS) studies comprising 106 DHS surveys between 1990 and 2002, showed that the mother's education and the father's occupation had a stronger effect on neonatal survival than on the other early childhood mortalities (post-neonatal infancy and under-five) (Mahy, 2003). As a specific example, Nepal's national data based on demographic and health surveys (2001, 2006 and 2011) has shown consistently higher neonatal mortality rates among the women living in rural areas; women with no education; those living in the mountains; the poor; indigenous ethnic and lower caste; those giving birth with less than two years' interval; and among the young women below 21 and older than 35 years (Paudel et al., 2013b). The neonatal mortality rates (per 1,000 livebirths) according to the 2011 NDHS report are higher in rural areas (rural 34, urban 23), among illiterates (illiterate 38, primary level or above 28), in the mountains (mountain 46, national 33), among the poor (least wealthy 33), among the indigenous/lower caste (indigenous/lower caste 36, non-indigenous/upper caste 26); and among the short spaced (<2 years interval: 54, >2 years interval: 23) (MOHP et al., 2012). These studies in Nepal have often described the mortality distribution according to different socio-demographic determinants. However, they are limited in describing mortality patterns, and lack in-depth socio-cultural explanations for what has led to these ongoing deaths in the high mortality groups, such as among poorly educated young mothers in the mountainous communities of the country.

Caste/ethnicity and material conditions

Social determinants such as caste/ethnicity, and material conditions such as housing condition, air pollution, and food insecurity are found associated with neonatal deaths. One large-scale earlier

study from India (Achyut, Lahiri, & Acharya, 1997) showed that families living in *Kachcha* houses (mud houses, often shared by people and cattle) and those without toilets were more likely to experience early neonatal deaths. The same study identified nearly a quarter of early neonatal deaths among the mothers of the scheduled caste—the so called untouchables in the Indian caste system. Poor sanitation measures during birth and the choice of damp and cold corners of the houses as a birth place increase the chance of hypothermia leading to coughs and colds, and infection in rural settlements with muddy houses, which are often without water supply and inside toilets. Scheduled caste families in India and Nepal are often the poor, illiterate and disadvantaged families. Sharing the house with cattle and giving birth in an animal shed in a damp and cold place increases the chance of neonatal tetanus. An earlier study in a mountain district of Nepal identified statistically significant higher risk of death associated with animal shed birth, higher effect for neonatal deaths than post-neonatal infant deaths (Thapa et al., 2000). This study identified animal shed birth as a common practice; nearly half of the women were found giving birth in an animal shelter, and the other half at home. Thus, the broader social determinants such as caste/ethnicity and material conditions such as housing type and amenities (water supply, toilet access) are found interacting and creating vulnerability to infections and deaths in rural communities. Other material conditions such as indoor air pollution (Boy, Bruce, & Delgado, 2002) are also found to create vulnerability to perinatal deaths. Indoor air pollution is associated with low birth weight, thus making newborns vulnerable to infections and subsequent death (Boy et al., 2002). Further analysis of Nepal's 2011 Demographic and Health Survey also found indoor air pollution to be a significant factor for neonatal deaths (MOHP et al., 2012).

Gendered culture and family dynamics

Gender is one of the major social determinants of health (CSDH, 2008). It influences reproductive behaviour, access to care and perinatal survival. Gender includes socially and culturally constructed roles that men and women play, and the relations that arise (Liverpool School of Tropical Medicine [LSTM], 1999). It is relational, dynamic, and the roles and relations are unequal and hierarchical. Examination of the gendered contexts comprises study of different behaviour, roles, responsibilities and expectations of men and women and their influence in health and sickness responses. Gendered roles and responsibilities shape access/resources, which in turn are shaped by gender based norms and values. Such a gendered perspective has been discussed more in relation to older children and maternal survival (Mosley & Chen, 1984; Pokhrel et al., 2005; Thaddeus & Maine, 1994). It is identified that male children have a 20% higher survival chance during the first and the fourth year of their age in India, Bangladesh, Nepal, Pakistan and Vietnam (Mahy, 2003). A range of studies from South Asian countries have discussed gender as an important factor impacting on maternal and child survival (Brunson, 2010a; Mahy, 2003; Pokhrel et al., 2005; Silverman et al., 2011; Simkhada et al., 2010). However, studies describing gender constructions and their influences particularly on perinatal survival are rare.

Evidence in Section 2.5 showed that the discourse about perinatal survival is dominantly focussed on the medical/epidemiological aspect. Only recently, the discourse has shifted from simply technical/bio-medical interventions to the broader understanding of health systems barriers and contexts. The purpose of this shifting focus is to facilitate the delivery of the interventions in the local health care systems. Perinatal survival is predominantly linked to bio-medical construction. Gender discourse targeting prevention of perinatal deaths is seen as less relevant. There could be different reasons behind this such as the policies and strategies which are predominantly medically guided; only the medical evidence may be considered as 'evidence' or as knowledge. Research to understand gender and socio-cultural contexts therefore receives less priority and may not be considered within the health care/medical domain.

Gender and sex preference

Some studies have indicated that gender influence is crucial even during the neonatal period. Despite a well explained biological survival chance of female babies (Fuse & Crenshaw, 2006; Ulizzi & Zonta, 2002), the survival chances of a girl child are compromised due to gender bias (Lawn et al., 2014). Strong preferential attitudes towards a baby boy pose a challenge to save baby girls both during pregnancy and after birth in South Asian countries. In Nepal, a study conducted in the southern plains district (Rosenstock et al., 2013) showed higher chances of death of male neonates during the early neonatal period, but the chances of deaths were shown to be higher for girl neonates during the late neonatal period. In many South Asian countries, girl children are disadvantaged (Arnold, 1992). They are perceived as financial burdens, and are often exposed to vulnerabilities of infections. The attitude towards son preference has influenced women and their families' behaviour to favour sex selective abortions. It has led them to use female infanticide and give less attention towards a girl child during illnesses. Gendered ideology and patriarchy is therefore reflected in every aspect of women's lives including in relation to care during pregnancy and birth (Barot, 2012; Pande et al., 2006). Widespread sex selective abortions and strong socio-cultural preference for a son are agreed as a cause behind millions of missing female babies in China (Nie, 2011). Legal steps and policy measures taken to reverse sex-selective abortions were unsuccessful in reversing the practice in India (Pande et al., 2006; Pörtner, 2015). The decrease in fertility is accompanied by increasing numbers of sex-selective abortions in earlier parities in both urban and rural areas, and more prominent among better educated women (with education of eight years or more) (Pörtner, 2015).

Gender and women's autonomy

After the International Conference on Population and Development (ICPD) in 1994, the gendered position of woman is acknowledged as crucial in personal health, overall reproductive health including in decisions regarding when to marry, whether, when and how many babies to plan (UNFPA, 2014). It is estimated that family planning (spacing, limiting births and delaying) alone

could avert 60% of maternal and 57% of child deaths (Stenberg et al., 2014). Unintended pregnancies and pregnancies at young age produce huge risks of maternal as well as neonatal and child deaths (UNFPA, 2013). However, women do not have the power to negotiate to protect their pregnancies in Africa and South Asia (Hussein, McCaw-Binns, & Weber, 2012).

In many developing countries, women's access to care during pregnancy, birth and the postnatal period is influenced by the decisions of their mother-in-law and husband (Bloom, Wypij, & Gupta, 2001; Thaddeus & Maine, 1994; Ware, 1981). In Nepal, Kaphle et al. (2013) identified the important role of mothers-in-law in supporting their daughters-in-law for birth preparedness, providing greater confidence, and ensuring safety during birth. Brunson (2010a) discussed men and women's cultural position as a barrier in the uptake of bio-medical care at birth. Brunson conducted her study in the Kathmandu valley of Nepal. Men did not view pregnancy and childbirth as their responsibilities, and women did not have the power to decide to seek care for childbirth. In a neighbouring district of the capital city in Nepal, Simkhada et al. (2010) discussed the role of the mother-in-law as being crucial in deciding on access to care during pregnancy.

The section below on gender and domestic violence expands further on gender and its relation to autonomy.

Gender and domestic violence

Gendered beliefs and values of patriarchy compromise women's autonomy, prevent them from accessing care, and in some cases women are abused such as being subjected to domestic violence during pregnancy. Cultural beliefs and values of a patriarchal society and the Confucian norms limit women's autonomy to make reproductive decisions in rural Vietnam (Graner, Mogren, Duong, Krantz, & Klingberg-Allvin, 2010). Similarly, in rural Uganda, lack of male support is described as a barrier in accessing pregnancy and childbirth services (Waiswa et al., 2008). A range of studies have revealed the association of domestic violence and abuse during pregnancy with birth outcomes, and of the utilisation of formal care with neonatal and infant survival (Ackerson & Subramanian, 2008; Ahmed, Koenig, & Stephenson, 2005; Jejeebhoy, 1998; Koenig et al., 2010; Lipsky, Holt, Easterling, & Critchlow, 2003; Melhado, 2005; Sarkar, 2013; Viellas, da Gama, Carvalho, & Pinto, 2013). Studies have also shown that domestic violence affects women's physical and psychological health (Ackerson & Subramanian, 2008; Stephenson, Koenig, Acharya, & Roy, 2008). This in turn affects their nutrition status, fertility intentions, contraceptive uses, and access to reproductive, maternal and child health services. Women's fertility intentions are controlled by the behaviour of their husbands, and those who suffer domestic violence are more likely to experience unintended pregnancies (Stephenson et al., 2008). The experience of foetal and infant loss among the victims of domestic violence reflects the worst consequence of unfair patriarchal systems (Jejeebhoy, 1998). Studies by Singh, Singh, and Mahapatra (2013a), Koenig et al. (2010) and Sarkar (2013) in India identified that women suffering abuse and violence during

pregnancy had poor uptake of prenatal care, and had poor chance of perinatal survival. Some studies also identified higher risk of LBW babies among the women experiencing violence during pregnancy (Lipsky et al., 2003; Melhado, 2005). It is also shown that the poor long-term child survival which is still causing a large number of foetal deaths and neonatal deaths in India's Uttar Pradesh region is attributed to women's low autonomy and increasing violence within marriage (Ahmed et al., 2005).

Gender and fertility behaviour

Gender is found intersecting with fertility behaviour and resulting in closely spaced pregnancies. Close birth spacing affects maternal, perinatal and child survival in a range of ways, such as sibling competition, maternal nutrition/folate depletion, sub-optimal lactation and transmission of infectious diseases among siblings (Conde-Agudelo, Rosas-Bermudez, Castaño, & Norton, 2012). Another review identified women with an inter-pregnancy interval shorter than six months as significantly more likely to have a risk of pre-term, low birth weight and small for gestational age (Conde-Agudelo, Rosas-Bermúdez, & Kafury-Goeta, 2006). Previous studies have shown that a birth interval of three years or more could prevent up to 40% of neonatal deaths (Shelton, 2005). This is confirmed in the research findings of a large scale survey by Yigzaw and Enquselassie (2010) that babies with short birth spacing (<15 months) were 16 times more likely to die during the first month after birth, even after stratifying for maternal age.

Birth spacing is affected by a range of social and economic conditions, such as the sex of the older child (Fayehun, Omololu, & Isiugo-Abanihe, 2011), residence status (rural or urban), tribe and ethnicity (Mairiga, Kullima, Bako, & Kolo, 2010), and availability of reproductive health services like contraceptives (Mairiga et al., 2010; Yohannes, Wondafrash, Abera, & Girma, 2011). In Nepal, the attitude towards son preference and women's growing interest to work outside the home was found associated with short birth spacing (Suwal, 2001). This study still did not reflect the situation in the most rural areas, such as mountain districts of *Karnali*. Likewise, the poor survival chances of children and a preceding birth of girl child in *Lgbo* and Southern minorities in Nigeria caused parents to shorten birth spacing (Fayehun et al., 2011). In the Nigerian *Lgbo* community, women tended to have short birth intervals and a large family size because of the fear they had of their babies' poor survival chances in their community.

Political commitment and leadership

Political commitment and leadership is seen as a broader social determinant influencing health care access and newborn survival. As already discussed, studies have explained that inadequate commitment to implementation of policies and expansion of intervention coverage has resulted in the slow rate of neonatal mortality reduction and the poor general coverage of essential neonatal interventions in the African and South Asian countries (Bhutta et al., 2014). Low priority of stillbirths is a concrete example of the poor political commitment and national leadership in many developing

countries (Frøen et al., 2016). Prevention of stillbirth has not yet become a priority agenda item in public health policy area in many developing countries. Despite being a low income South Asian country, the success of Sri Lanka in reducing its maternal and neonatal mortality is attributed to its political commitment and leadership in health, education and social welfare (Caldwell, 1986; Pathmanathan & Liljestrand, 2003). No other South Asian countries have yet reached the level of success Sri Lanka achieved by the 1980s despite the fact that the country went through a protracted civil war for many years. The national commitment for sustained investment in PHC and women's health, prioritisation of women's education and empowerment, and the leadership role of professional organisations, research institutes and academia, have contributed to significant improvement in maternal and neonatal survival (Pathmanathan & Liljestrand, 2003).

Newborn care practices influenced by socio-cultural contexts

The section above about 'Gendered Culture and Family Dynamics' described that gender norms, beliefs and values in poor settings compromise the access and utilisation of appropriate care. The gender norms and values negatively affect the nutrition behaviour, and weaken the protection mechanism that makes mothers and their babies vulnerable to poor health and survival. Mother's postnatal practices, including newborn care behaviours, are also socio-culturally shaped. In rural Karnataka in India, early bathing, unhygienic cord cutting and delayed breast feeding were common cultural practices (Kesterton & Cleland, 2009). Ghosh (2012) comments that adverse cultural norms and practices about newborn care have attributed to India's sluggish decline in the neonatal mortality rate. A study from rural Bangladesh (Winch et al., 2005) identified that newborns and mothers were confined inside the house, normally in the place of birth rather than in mother's bedroom, for up to seven to nine days after birth. Chances of accessing health care during the critical first week after birth are compromised due to such confinement. The same study identified that newborn babies were believed to suffer from evil eyes and spirits, and the mothers' foods and drinks were related to hot and cold food taboos. Pre-lacteal feeding is a commonly reported barrier to sub-optimal breast feeding by families in Muslim and Hindu communities in South Asia (McKenna & Shankar, 2009). Similarly, a study from Ethiopia explored that mothers had a strong belief about the placenta as the baby's house (Degefie et al., 2014) and so breastfeeding was delayed until the placenta was delivered. The same study identified that babies were not properly wrapped with clean and dry clothes. Newborns were bathed with frequent cold water baths, and hygiene practices, such as hand washing, were not maintained while handling newborns. Another study from Uganda explored parents as well as health workers not accepting 'delayed bathing' and 'putting nothing on the umbilical cord' as the proposed measures for care of newborn babies (Waiswa et al., 2008).

Likewise, the family's perception and pessimism about poor survival chances of a sick child was found to be associated with delayed care seeking in northern India (Aggarwal et al., 2003). Fatalism around care seeking, especially for a premature newborn, and for a sick child is

commonly reported in developing countries (Dickson et al., 2015). Such beliefs and experiences indicate that maternal and neonatal related policies and interventions must be tailored to the local contexts (Kouéta et al., 2010; Sousa & Nations, 2011; Waiswa et al., 2008).

Overall, this section on socio-cultural views showed that improvement in poor perinatal survival is embedded in socio-cultural contexts. Evidence is growing on the importance of addressing SDH to advance perinatal survival. The major causes of perinatal deaths such as infection, low birth weight and delayed treatment of birth complications, stem from socio-cultural roots. Socio-demographic determinants and a range of broader social determinants, such as place of birth, poverty, caste/ethnicity, gender and political commitment impact on poor perinatal survival. The care practices during birth and neonatal care are influenced by socio-cultural contexts. The socio-cultural focus has been also emphasised as a key basis in maternal and child survival models which are equally relevant in perinatal survival. In addition, there are growing realisations to complement bio-medical causes with socio-cultural aspects. Such a context leads investigation of the topic in this thesis framed within social constructionism and a critical theoretical perspective, which are expanded in the following section.

2.5.3   Theories Influencing Knowledge Constructions in this Thesis

It can be seen from the research discussed that poor perinatal survival in developing countries is not just a medical or epidemiological issue. It is an issue of inequity and injustice that stems from health care systems and socio-cultural contexts. Therefore, it is appropriate to situate this thesis framework within social constructionism and critical theoretical perspectives as outlined below.

Social constructionism

Social constructionism is a framework that implies that knowledge is constructed through interactions among individuals who are engaged in its construction (Bryman, 2016). Bryman adds that reality is a social product under continuous construction and re-construction during the ongoing interaction of social actors, and that it has no built-in essence. This framework views knowledge as historically and culturally situated; local, specific and co-constructed realities with consensus among those engaged in construction; and aiming to reveal or understand the phenomenon (Burr, 2015; Lincoln, Lynham, & Guba, 2011). The epistemological position of constructionism guides a researcher to understand how participants engaged in an interaction construct meanings and make sense of their own world from differing perspectives (Crotty, 1998). Crotty (1998) emphasises the focus of constructionism as construction of meaningful reality in engagement with the world and the objects in the world. The focus is on continuous interactions and contacts that can develop actual meaning, and both the subjective and objective meanings (truths) are held together indissolubly. Boghossian (2001) and Mallon (2007) describe an idea as socially constructed, meaning that it is contingent on social selves. The social selves comprise culture, human decisions, values, beliefs, texts and meanings that people co-create through their

own choices in interactions, thus allowing the possibility of making differing constructions about what they construct as their current realities, values and beliefs.

Gergen and Gergen (2007) describe the convergence of three key movements in social constructionism: (i) critical—to the work of Frankfurt School and Foucault (Bronner, 1989); (ii) literary/rhetorical—use of the language; and (iii) social—social processes creating knowledge as the basis for social constructivist's inquiry. They presented at least four key arguments that shape the scholarship within social constructionism. First, the social construction of knowledge— knowledge is produced from human relationships, a communal view of knowledge. Second, constructionism considers language used in relationships as a central feature in the construction process. Meanings are considered the derivatives of the language used in relationships. Third, the political economy of knowledge, evolving nature of knowledge, and not a God's eye view of truth, but to examine it as to whether it affects human lives. Fourth, constructionism shifts the focus from the individual actor to the relational self, where "a truth or knowledge" is produced from a process of coordination. Thus, today's reality is the result of an agreement of different individuals (co-construction), often culturally and historically situated, but it can be changed for the betterment of the people.

This thesis aims to recommend changes in such co-constructions for improving perinatal survival in Nepal's mountain villages. Lock and Strong (2010) describe meaning making and understanding as a central feature of social constructionism which is produced from social interactions and consensus. Meaning making is situated in specific socio-cultural contexts to a particular time and place, and individuals involved in interactions are considered socially constructed participants in their shared lives. In this thesis, I view women and families' perceptions and experiences about poor perinatal survival as a socially constructed reality in the mountainous villages of Nepal. This thesis aims to explore and examine the factors that have been socio-culturally constructed about the poor perinatal survival in the villages.

Critical theoretical perspective

In a critical perspective, reality is viewed as virtual, and is shaped by socio-political, cultural, gender, economic and ethnic forces (Lincoln et al., 2011). It allows dialectical methods to generate knowledge. Critical researchers assume knowledge as being power mediated (Kincheloe & Mclaren, 2011). They view the boundary between facts and values as inseparable; the relationship between a concept and an object as an ever changing and evolving process; and language (discourse) as central to subjectivity formation (construction of individuals' selves). Such researchers are aware of the persistence of oppression and domination that leads the dominated groups to continuously accept their own status as natural or inevitable. For example, the acceptance of perinatal deaths and the socio-cultural context of the subjugated motherhood of women as factors for persistent perinatal deaths in the villages, which will be discussed in

Chapters Six and Seven of this thesis. Critical researchers are guided by an ethical imperative: they question conventional wisdom, refuse to identify freedom from any institutional or a fixed system of thought (Bronner, 2011). Such a framework allows freedom to see a phenomenon from multi-disciplinary perspectives by drawing from the disciplines of anthropology, sociology, cultural theory, philosophy and political economy to seek the emancipatory alternatives from the existing order (Bronner, 1989, 2011).

> In fact, critical theory is not a single doctrine or unified worldview. Instead, it is a set of basic insights and perspectives which undermine existing 'truths'. (Bronner, 1989, p. 3)

The critical theory perspective evolved rapidly during the late 1980s with the critiques that unfair assumptions of post-positivist research tradition do not fit marginalised individuals or groups (Bloomberg & Volpe, 2012). The women and their family members experiencing perinatal deaths in the remote Mugu district of Nepal comprise such groups. In the post-positivist tradition, the forces behind marginalisation, such as the socio-cultural factors associated with the experience of persistent inequity in perinatal survival among the mountain women are taken for granted. A critical stance is a perspective that questions taken-for-granted assumptions (Burr, 2015). Such a perspective is intertwined with politics, and assumes that research brings reform that can change the lives of participants, institutions and communities (Bloomberg & Volpe, 2012) as intended in this thesis.

Studies with a critical theoretical perspective have a focus on social justice (Creswell, 2014; Hesse-Biber & Leavy, 2011) and hence are relevant to the aims of this thesis. Researchers taking a critical perspective aim to design research projects as a stimulus for change and advocacy; they accept knowledge as value mediated; and seek the importance of historical insights (Polit & Beck, 2012). Perinatal survival is an issue of inequality and injustice across many developing countries including Nepal. What appears as medical truth behind the deaths of many babies, such as diarrhoea, pneumonia, infections, birth trauma, asphyxia, which the available literature dominantly discusses, does not entirely capture the social and cultural forces, which have led to continuous perinatal deaths in rural areas. The study villages in this research are located in a remote, rural and disadvantaged mountainous district of Nepal. The assumption of critical theoretical perspectives constantly reminded me of the reflexivity in this research, insight into historical context, and the purpose—empowering people and improving their lives in the mountain villages.

Through this lens, as Thomas (1993, p. 5) describes, use of a critical perspective facilitated me not just to satisfy pondering into 'what is this?', but to evolve from here and to ask 'what could this be?'. This guided the study to investigate perinatal deaths by wearing a lens of possibility to break apparent cultural meanings and behaviour and to situate the investigation in historical and cultural contexts—that is to understand what elements in their historical and cultural contexts have led

women and their families to bear the trauma of persistent deaths of babies in the mountain villages.

2.6 Conclusion

To conclude, the chapter has presented a review of literature on poor perinatal survival in the context of developing countries. It has expanded an understanding of the current global picture, interventions and strategies used in preventing ongoing perinatal deaths. Evidence has shown a range of proven interventions available to prevent perinatal deaths. The research, initiatives and frameworks/models have elucidated a growing importance and evidence about social determinants to address poor maternal, neonatal and child survival. Literature identified that the epidemiology is fairly well known and proven interventions are available. In this regard, the Every Newborn Action Plan's ambitious global and national targets of reaching universal health care coverage and ending every preventable perinatal death may be reached in developing countries only by understanding socio-cultural and health care contexts in which perinatal deaths continue to occur. The growing concerns in relation to inequity in perinatal survival outcomes in developing countries particularly in rural and disadvantaged population groups/subregions, as highlighted in the literature, could be effectively addressed by tailoring their health systems into local socio-cultural contexts. It is also evident that socio-cultural and health care contexts could be unique to each place. Literature strongly indicated the need to understand implementation contexts of perinatal interventions and strategies in local settings with the views about them from families and communities. In this regard, it is seen that a research focus on perinatal survival is essential to understand local socio-cultural contexts and inter-relationships between factors rather than merely identifying a pattern (distribution) of mortality or care utilisation. This chapter has also discussed the way this thesis is framed within socio-cultural and critical theoretical perspective.

Having established the theoretical background for the study, the following chapter discusses research approach and study methods used in this thesis.

METHODOLOGY

The previous chapter discussed the literature providing the background and significance of the present study. The literature indicated an urgent need to prevent the large prevalence of perinatal deaths, as well as an increased attention to improving the quality of perinatal care. There is a growing acknowledgement that a perinatal death is an indication of inequity and injustice; it is underpinned by social determinants and is a public health problem. A range of studies identified the importance of addressing health system barriers, socio-cultural factors and their incorporation into policies and programmes to prevent ongoing and high perinatal deaths in developing countries. The previous chapter also discussed commonly employed models/frameworks in maternal and child survival and the theoretical perspectives shaping this thesis. The present chapter discusses the overall study design and provides comprehensive information on the methodology, research procedures and methods used to conduct this study. The chapter briefly describes how the chosen theoretical perspectives guided this thesis, presents qualitative methodological approach used in this study, and discusses three common underpinning principles as methodological principles from the chosen perspectives: the researcher's reflexivity, participants' experience as knowledge, and the experiences about perinatal care and survival as events that could be inquired through naturally occurring interactions at a field setting. The remainder of the chapter describes the study fieldwork including recruitment strategies, data collection techniques, data analysis and ethics, and concludes with limitation and a brief chapter conclusion.

3.1 Theoretical Concepts

This thesis utilises social constructionism and critical theoretical perspectives to examine the socio-cultural and health care contexts of poor perinatal survival. The goal of this thesis is not only to examine socio-cultural and health care contexts, but also to draw implications to the prevention of ongoing perinatal deaths in the mountains of Nepal. This thesis aims to unravel factors beyond bio-medical and how they have impacted on poor perinatal survival among the women and their families in the mountainous areas of Nepal. This required the research to be located within a social constructionism and a critical theoretical framework as discussed in Chapter Two, Section 2.5.3. The use of these concepts allowed the valuation of the experiences of participants—women, their family members and health service providers working in the remote mountain villages, thus fitting into the socio-cultural approach of this thesis. Social constructionism has guided me to produce knowledge (constructs) in this thesis from a negotiated understanding of how women and their

family members view a perinatal sickness and death—what it is to them, why it happens, and the ways they rationalise it. A critical theoretical perspective has guided me to situate findings in discussion that lifts it up from the current overwhelming bio-medical descriptions about what cause perinatal deaths: infection, low birth weight and mother and child complications to the underlying structure and forces behind a continuous experience of a poorer level of perinatal health. The findings and discussion revolves around underlying/ structural forces such as religious indoctrination related to *Karma, Dewata* (God) in Chapter Six, gendered constructions of perinatal survival in Chapter Seven, and role of health systems (including accountability and declining primary health care approach) in contributing to ongoing perinatal deaths in Chapter Eight.

3.2 Research Approach

There are two key approaches to investigate perinatal survival, namely bio-medical approach and qualitative socio-cultural approach. The present study is based on a qualitative methodological approach guided by theoretical concepts of social constructionism and a critical theoretical perspective. The qualitative methodological approach is appropriate to explore naturally occurring data, the behaviour and interactions which are understood in real world settings (Bloomberg & Volpe, 2012, p. 30; Denzin & Lincoln, 2011; Patton, 2015; Ritchie, Lewis, Nicholls, & Ormston, 2013; Van Olmen, Marchal, Van Damme, Kegels, & Hill, 2012, pp. 49-50). Qualitative methods are also appropriate to understand the subjective experiences, meanings and interpretation of individuals including those from vulnerable groups (Liamputtong, 2007, p. 7; Van Olmen et al., 2012, p. 60). The present study has sought the beliefs and experiences of women and their families in two selected mountain villages of Nepal, and the frontline health workers who went through the experience of perinatal deaths. The in-depth nature of the qualitative method allowed me to explore participants' experiences surrounding care in pregnancy, during birth and the postnatal period, and their views and beliefs about perinatal deaths. A qualitative approach allows a researcher to listen to the voices of unheard, silenced and marginalised groups (Liamputtong, 2010; Van Olmen et al., 2012), such as those in this study from the remote villages. This approach is considered suitable for understanding participants' experience in a much less intrusive way and in a way to empathetically listen to them and relieve them from their supressed pain (Liamputtong, 2010) .

The qualitative methodological approach is also appropriate for the socio-cultural approach of this thesis, which seeks to examine the contexts of poor perinatal survival through participants' meaning and experience. The underpinning theoretical concepts are also congruent with this methodological approach. This required an understanding of complex interrelationships across different factors woven into women, their family and institutions which qualitative research design can deliver. Qualitative methods provide a reflexive engagement of researchers with participants, and provide complex and detailed descriptive, exploratory and process oriented data (Hesse-Biber

& Leavy, 2005). As described by Hesse-Biber and Leavy (2005, p. 28), what qualitative methods ask is beyond just describing "what it is" but more importantly explain, "how, why, what the process is and, what the significance is". This thesis sought to examine the complex socio-cultural and health care contexts of perinatal deaths to answer why babies continue to die in the mountain villages. Using such an approach, enabled me to gain a clearer understanding of the experience of informants, which Liamputtong (2007) argues can offer access to the rich and complex data required to answer the research questions. To understand why and how babies continue to die in the mountain villages, this thesis draws on the holistic perspective which according to Fetterman (2010) allows a researcher to go beyond the immediate cultural scene, conduct intensive fieldwork, engage with the participants and consider the social whole. This enables a researcher to simultaneously account for the part and the whole system in order to obtain complex, process oriented data on providing and receiving health care. This provided me an adequate ground to critically investigate this issue across family and the health institutions in the study villages.

Poor perinatal survival is a global public health issue. A public health approach is a socio-political approach integral to society, politics and culture (Baum, 2016; Tod & Hirst, 2014). It demands collective efforts of lay people, professionals and stakeholders; and considers social justice as the foundation. Investigating a public health issue is becoming increasingly complex, requiring a range of methodological strategies to enable researchers to conduct rigorous research (Baum, 2016). Baum argues that singularity of method does not answer the multi-disciplinary socio-political nature of public health issues. It requires use of research approaches beyond just epidemiological methods to better understand the structural and cultural factors affecting health and diseases. In such a context, a range of authors (Baum, 2016; Faltermaier, 1997; Green & Thorogood, 2014; Liamputtong, 2017) discuss a growing relevance of qualitative research in public health to understand the process and user's views of interventions, to explore effective disease prevention and health promotion strategies, and to understand individually based and contextualised knowledge. More specifically, Baum (2016, p. 202 cited from National Health and Medical Research Counicl [NHMRC], 1996, p.13) describes four main ways that qualitative research can be used in public health: (i) to study and explain socio-economic, political and cultural factors influencing health and disease; (ii) to understand how individuals and communities interpret their health and disease; (iii) to elaborate causal hypotheses emerging from epidemiological and clinical research; and (iv) to provide contextual data to improve the validity and cultural specificity of the quantitative survey instrument. Therefore, in this study, a qualitative research approach was considered appropriate to examine the perspectives of women, family members and health care providers about perinatal deaths.

A biomedical approach is a "positivist, reductionist way of seeing a phenomenon. This approach believes in breaking a phenomenon into constituent parts, measuring them and then establishing a causal relationship" (Baum, 1995, p. 461). The biomedical model views health as the absence of

disease; it believes that illness emerges from bodily abnormality and has a clearly defined cause (Tod & Hirst, 2014, p. 4; Wade & Halligan, 2004). DiGiacomo (1999) reflects on the naturalistic epistemology[3] of the epidemiological approach, and argues that this approach has sought even to factorise and medicalise culture, and has reduced the possibility of an interdisciplinary approach to research. Considering the focus of this thesis, it is clear that the biomedical approach is limited in encapsulating a social and cultural understanding of the problem (Green & Thorogood, 2014, p. 214; Popay, Williams, Thomas, & Gatrell, 1998). Use of qualitative research approach, such as the Rashomon technique (Rusman et al., 1999) is useful in exploring women, families' and health care providers' differing views about a child's death. The Rashomon technique, derived from a Japanese drama based film' Rashomon', discovers often differing and multiple subjective versions of a single incident. Rusman and colleagues applied this technique in exploring reasons behind high infant deaths in the Upper Lombok region of Indonesia. A qualitative interview to understand the views from different witnesses of infant death was the key method used. Whereas, the biomedical approach takes an objective view in collecting data and ignores subjective experiences, which for this thesis would mean missing the voices of women and families who lose their babies, and the experiences of service providers working in the remote mountain regions. This study collected participants' subjective accounts adopting a socio-cultural orientation on what has influenced poor perinatal survival in the villages; and which could be better understood by a qualitative methodological approach.

3.3 Methodological Principles

Reflexivity in research

Finlay and Gough (2008, p. 1) describes reflexivity as: "a challenge to conventional ideals of science which favours professional distance and objectivity over engagement and subjectivity". Reflexivity is a key element, a defining feature in qualitative research, and is considered to be crucial in both constructionist and critical research traditions (Alvesson & Sköldberg, 2009; Denzin & Lincoln, 2011; Finlay & Gough, 2008; Pillow, 2003; Probst & Berenson, 2013). The necessity for reflexivity became crucial to deal with the triple crisis in qualitative methodology which Denzin and Lincoln (2000, p. 17) describe as "crisis of representation, legitimation and praxis".

According to Finlay and Gough (2008), doing reflexivity is to apply reflexive practice in each stage of the research process. It invites an acknowledgement of how a researcher comments on his/her multiple selves, and co-constructs his/her findings. This is to describe a researcher's personal accounts, decisions and dilemmas of the fieldwork, and a description of how s/he intersects and becomes the insider (Finlay & Gough, 2008, pp. 4-5). It requires critical self-reflection of the ways

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[3] Naturalistic epistemology emphasises the application of methods, knowledge and results of empirical evidence.

in which a researcher's social background, positioning, behaviour and assumptions impact on the research process. Finlay and Gough (2008, pp. 6-18) suggest five reflexive positions: introspection—examining personal experiences and meanings; inter-subjective—exploring meanings emerging on research relationships; collaborative reflection—recognising the informant's potential of becoming reflective; reflexivity as a social critique—situating reflexivity in critical theoretical perspective; and discursive reflexivity—reflecting the ambiguities and multiple meanings of language.

Related to Finlay and Gough's reflexive position in critical theoretical perspective, other researchers, such as Alvesson and Sköldberg (2009) and McCabe and Holmes (2009) discuss that a researcher needs an awareness of the socio-political characteristics of research. Such awareness is considered as a key element to reflect in terms of whether the research contributed to realising an emancipatory aim and to do a social justice in the way this thesis aims to contribute to the knowledge of women and families of the remote mountainous region of Nepal which records one of the highest perinatal death rates in the world.

In addition, Alvesson and Sköldberg (2009) discuss careful interpretation and reflection as underpinning values in qualitative research. The interpretation involves being aware of the pre-understandings, assumptions and languages. Reflection is thinking about thinking, the interpretation of interpreters, thus turning inwards towards the person of a researcher and research community. Unlike the positivist researchers' clearly stated research plan at the start of the study, the qualitative research continues to unfold during the process. Due to this emerging nature, researcher's decisions are crucial at every stage. Therefore, this makes researcher the key research instrument in qualitative research. The researcher is invited to become aware of the process during which the empirical knowledge is constructed, interpreted and written. In the process of knowledge production, it is assumed that there is no value free fact and fact free value. Therefore, reflexive practice is discussed as to be aware of the complex relationship between the engagement of a researcher and the process and various contexts of the research process. More specifically, it involves reflection about research technique such as for analysis, primacy of interpretation, research goal and modes of reasoning (deductive, inductive or abductive), (Alvesson & Sköldberg, 2009).

Berger (2015) discusses the use of reflexivity as a quality control strategy in qualitative research. Berger suggests practising reflexivity under three types of a researcher's positions: when a researcher shares the experience of research participants; changes his/her position such as from outsider to insider in the research process; and has no personal familiarity or experience with what is being studied. Hesse-Biber and Leavy (2011) describe reflexivity as an embedded holistic and transformative process in qualitative research. Research is not just the results, or findings are learnings; the research process itself becomes learning. Research is considered as a process,

rather than sequential steps. The researcher views all choices from topic selection to the final presentation as related. In this study process, the understanding of research process provided me a sense of confidence. In practising reflexivity, Day (2012) suggests asking reflexive questions about thinking—the epistemological assumptions about the production of knowledge (process), doing—the reflective accounts of the research relationship (researcher's multiple positions); and evaluating—validity and quality of qualitative methodology. In this study, awareness of these reflexive strategies helped me to reflect through the research process; and helped to make the emerging research process a transparent endeavour.

Experiences as authentic source of knowledge

Participants' experiences are valued as the authentic source of knowledge in this study. Qualitative methodology seeks subjective experiences, meanings and interpretation of participants (Denzin & Lincoln, 2011; Liamputtong, 2010; Patton, 2015). It gives value to their voices and opinions, which is also congruent with ontological assumptions of the theoretical concepts described in Chapter Two, Section 2.5.3. The theoretical concepts describe that truth lies in meanings that individuals construct, and these are subject to ongoing reformation and reconstruction.

In the postmodern era, individuals' accounts, experiences and perceptions are valued as truths (Grbich, 2004). Grbich discusses rejection of grand narratives and generalisable truth and a shift towards mini narratives that is from one single generalisable truth to multiple truths, thus valuing individuals' accounts and experiences as multiple truths and realities in everyday life. Experiences of women and their family members, the health volunteers and service providers from the remote villages are valued as knowledge in this study.

A range of studies (Lawton, 2003; Popay & Williams, 1996; Popay et al., 1998; Putland, Baum, & Ziersch, 2011; Williams & Popay, 2006) has discussed lay knowledge as crucial to understanding and addressing social inequities in health. This is important to understand insights into sickness experience of an individual to broader socio-cultural aspects of health and health care. Popay et al. (1998, p. 619) describe that a lay perspective offers "a vitally important but neglected perspective on the relationship between social contexts and the experience of health and illness at the individual and population level". It is argued that lay narratives provide "explanations for what people do and why–and which, in turn, shape social action" (Popay et al., 1998, p. 619). This elucidates the importance of capturing lay perspectives and experiences about individuals' contexts of health and illness. In addition, giving value to the lay knowledge situates research in a critical and constructionist's qualitative research tradition. Williams and Popay (2006, p. 125) identify the epistemological and political challenge of lay knowledge. By epistemological challenge, they meant a challenge to the experts' objective view of knowledge that undermines lay knowledge. By political challenge, they mean challenge to the authority of experts, to the institutional power. This introduces a shift in discourse from a passive understanding as lay beliefs

to the thinking of lay knowledge (Popay et al., 2003), thus valuing the experiences of the participants as authentic knowledge, such as of the experiences of women and their family members as sought in this study.

The experiences surrounding perinatal care and survival are naturally occurring interactions

A socio-cultural approach of studying a phenomenon in a real world setting is described as a naturalistic methodological approach. Such an approach is useful in understanding social actions, meanings, characters and nature of social life by "first hand eyewitness accounts of 'being there'" (Schwandt, 2014, p. 240). Interactions in natural settings provide rich description of social realities as they happen (Bryman, 2016; Lincoln & Guba, 1985). By natural settings, it is meant that a researcher explores the experiences and meanings "in some setting that is not contrived, manipulated, or artificially fashioned[4] by the inquirer; hence, the setting is said to be 'natural' or 'naturally occurring'"(Schwandt, 2014, p. 238). (Patton, 2015, p. 48) describes that the phenomenon of interest unfolds naturally through interactions taking place in real-world settings where:

> …the researcher does not attempt to affect, control, or manipulate what is unfolding naturally. Observations take place in real-world settings and people are interviewed with open-ended questions in places and under conditions that are comfortable for and familiar to them.

Data in naturalistic inquiry comprise the extracts of naturally spoken language, such as informal chats, observations in field settings, interview transcripts and introspections or reflections done at any stage of the research process (Brewer, 2000). This study utilised the experiences of women and their family members and health service providers about what has influenced poor perinatal survival by interactions in a natural field setting of the villages in Nepal.

This thesis views perinatal deaths as socially constructed realities, mediated by different socio-cultural forces. Perinatal survival is an outcome of health and social care that a woman receives during her pregnancy, birth and postnatal period, which is unique to each individual's day to day socio-cultural realities. Social care includes care and support from the immediate family who are the closest to the woman and her newborn child at the time surrounding the event of birth. Oakley (1984); Riessman (1983); Walsh, El-Nemer, and Downe (2004) discuss pregnancy and childbirth as socially constructed realities, which is understood in natural field settings through naturally occurring interactions. In addition, more recently, a range of researchers have reaffirmed pregnancy and childbirth experiences as naturally occurring interactions (Brubaker & Dillaway,

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[4] A setting is considered contrived, manipulated, or artificially fashioned where human actions are not studied in real world setting of people's day to day lives. Studies investigate actions which are controlled such as in experiments and lab investigations.

2009; Kaphle et al., 2013; Mansfield, 2008; Morton & Hsu, 2007). Morton and Hsu (2007) argue that childbirth education is a cultural phenomenon. The educational content, format and presentation are shaped by the cultural contexts of deeply woven values and beliefs related to childbirth. Likewise, Mansfield (2008, p. 1084) argues for childbirth as a social practice, inevitably embedded and influenced by social elements. The author described social elements as inevitable experiences in childbirth, occurring in terms of "activity during birth, preparation before birth, and social support, both in an individual and in a broader socio-cultural sense". Similarly, Kaphle et al. (2013) have described women's subjective experiences of childbirth as natural interactions, and indicated that such interactions were imperative to understand care and survival of both mother and babies. Kaphle et al. (2013) describe the birthing experiences as constructions from day to day interactions with women, their families, and service providers. Likewise, from the studies of Haws et al. (2010); Liamputtong (2000); Rusman et al. (1999), it is evident that perinatal deaths have been described as culturally constructed realities. Such deaths are attached to cultural meanings and interpretations, which could be understood from their stories explored through natural conversations.

This study views that experience of women, their families and providers regarding what has led to ongoing perinatal deaths could be examined in a fieldwork setting by their stories of everyday experiences. The fieldwork setting and the stories of day to day experiences affirmed a natural setting and a naturalistic methodology. In the remote mountainous villages of Nepal, perinatal deaths were observed as everyday realities experienced by the participants. The stories of the participants have been valued and considered as authentic sources of knowledge to examine socio-cultural constructions related to perinatal deaths, and thereby to understand vulnerabilities for poor perinatal survival. The natural interactions also allowed me to respect participants' socio-cultural circumstances in their everyday lives, and which helped to collect rich data to examine the socio-cultural contexts.

3.4 Recruitment of Study Participants

3.4.1 Participant Selection Strategies

There are different sampling strategies according to whether a study adopts a qualitative or quantitative methodological approach. Sampling in a quantitative study is straightforward. The decision about the type and size of respondents is fixed at the beginning of a study (Patton, 2015; Ulin et al., 2012). In a quantitative study, as the main purpose is generalisation, the logic and power is about selecting a truly random and statistically representative sample. In contrast, the purpose of a qualitative study is to select information-rich cases to explore and understand a phenomenon in its breadth and depth as decided by the purpose of the study (Patton, 2015). In this sense, all qualitative sampling strategies could be considered purposive.(Patton, 2015, p. 264) describes:

The logic and power of purposeful sampling lies in selecting information-rich cases for in-depth study. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the inquiry, thus the term purposeful sampling.

Although the overarching strategy in qualitative study is based on purposive sampling, it does not happen in a linear and specific steps as in quantitative study (Coyne, 1997; Patton, 2015). Although a general prior thinking is required, actual sampling process emerges when a researcher enters in the field for data collection. The context in the field, accessibility of cases, and the researcher's reflection and evolving theoretical need determine the nature of successive cases to be selected. Coyne (1997) presents a range of sampling strategies used in qualitative studies as follows (Table 3.1).

Table 3.1 Various qualitative sampling strategies

Author/s	Strategy
Straus and Corbin (1990)	Theoretical Sampling in three stages • Open sampling • Relational and variational sampling • Discriminate sampling
Paton (2015)	All sampling is purposeful sampling—8 strategic types and 40 different strategies • Single significant case sampling (e.g. critical case, index case, high-impact case, teaching case) • Comparison focussed sampling (e.g. outlier sampling, intensity sampling, positive deviance sampling, criterion sampling) • Group characteristics sampling (e.g. maximum variation sampling, homogeneous sampling, typical case sampling, key informant sampling, quota sampling, purposeful random sampling) • Theory-focussed and concept sampling (e.g. deductive-theoretical/inductive-theoretical sampling, causal pathway case sampling, principles focussed sampling, ripple effect sampling) • Instrumental-use multiple case sampling (e.g. utilization focussed sampling and systematic qualitative evaluation reviews) • Sequential and emergence-driven sampling (e.g.snowball or chain sampling, opportunity

	sampling)
	• Analytically focussed sampling (e.g. confirming and disconfirming cases, sampling politically important cases
	• Mixed, stratified, and nested sampling strategies (e.g. combined or stratified purposeful sampling)
Morse (1991)	Four types:
	• Purposeful sample
	• Nominated sample
	• Volunteer sample
	• Total population sample
Sandelowski et al. (1992)	Two types:
	• Selective sampling
	• Theoretical sampling
Sandelwoski (1995)	All sampling is purposeful—three kinds
	• Maximum variation
	• Phenomenal variation
	• Theoretical variation

Source: Adapted from Coyne (1997)

Theoretical sampling

It is evident from Coyne's discussion that the terms selective sampling, purposive sampling and theoretical sampling have often been used interchangeably. However, theoretical sampling is attached mainly to the discovery of grounded theory (Glaser & Strauss, 2017). In theoretical sampling, a researcher starts data collection from an initial sample in a locale where the phenomenon occurs, and then proceeds to follow the theoretical sampling strategy as dictated by emerging theory. It involves simultaneous collection, coding and analysis of data. Coding is done from raw data. The successive coding informs the researcher about the next sample, and this continues until each evolving category is saturated. Saturation is confirmed by testing a category with incoming data, and not against a list of variables.

Glaser and Strauss describe saturation in relation to a phenomenon of investigation and categories to generate a theory from data (Glaser & Strauss, 2017).Theoretical sampling is purposeful in a sense that each additional sample is chosen to inform the emerging theory. Yet, Marshall (1996) argues that though theoretical sampling is mainly attached to grounded theory, this is used in some forms by most qualitative investigations where interpretations are essential. It is discussed that there is no one-size-fits-all strategy regarding saturation (Fusch & Ness, 2015). One simple approach to confirm saturation is that when no new data emerge, it means no new themes are likely to emerge. Rather than thinking saturation in terms of size of sample, Fusch and Ness discuss that saturation is affected by both quality (rich) and quantity (thick) of interviews. In this regard, they also relate triangulation—an approach to gain multiple perspectives about a topic of study, as a means to reach data saturation.

Priori sampling

Besides Coyne's list, Ulin et al. (2012) describes priori and theoretical sampling strategies. The latter is consistent with the goal and technique of grounded theory. Priori sampling strategy that Ulin et al. (2012) recommends is more specific to applied public health research; and resembles what Paton (2015) describes as criterion based sampling. In a priori sampling strategy, Ulin et al.'s emphasis is on a researcher's anticipation of some criteria to select suitable participants and their structure based on the research problem and purpose. However, flexibility is the key to selecting specific cases for richness of information and to offer explanatory value.

Blended approach of priory sampling strategy with the theoretical sampling

In this study, the category of participants deemed appropriate were identified before the start of the study as suggested in Ulin et al.'s description of the priori sampling strategy. The key category of the potential participants were anticipated, and outlined in the proposal submitted to the ethical boards at Flinders University, the Social and Behavioural Research Ethics Committee (SBREC) and the Nepal Health Research Council. The key priority was to recruit women who had themselves experienced perinatal death, and therefore had gone through pregnancy and childbirth

experiences. The intention was to construct a sample which varied both by professional group and by community to gather different points of view with regards to perinatal death, and reveal complex data about socio-cultural and health care contexts of perinatal deaths. The following key features were considered in the invitation and selection of the participants in this study.

- Village women and their family members who experienced a perinatal death (stillbirth plus any neonatal deaths during the first month after birth) from the study villages and who expressed their willingness to participate in the study;
- Health service providers such as the district manager, medical officers, nurses, midwives, assistant health workers including female community health volunteers and traditional healers from the study villages and district hospital who agreed to participate in the study; and
- Local stakeholders such as staff of non-governmental agencies working in the field of maternal and neonatal (child) health, local politicians and journalists who showed their willingness to participate in the study.

The participants' criteria described above were to locate a sampling frame (Devers & Frankel, 2000) in the villages. However, the actual selection process was a demanding task as illustrated in the recruitment process (Figure 3.1) described below.

Qualitative researchers utilise different sampling strategies at different stages of their research (Ritchie et al., 2013). It could be open and unstructured at the start, and become more purposive and discernible as a study progresses (Van Olmen et al., 2012). It is argued that the key is to select information-rich cases (Patton, 2015). This is affected by study purpose, availability of resources, questions asked and constraints faced. This occurred in this study as well. As I spent five months for the fieldwork, the initial interviews with women (see participants type in Table 3.2 in the next section) and informal chats at health facilities led him to choose a participant who was a local activist in child marriages, and a local college teacher who was a sociologist with knowledge about faith healing, child marriage and family dynamics. I also interviewed two women although they had no recent perinatal losses (in the last five years), and another woman although she did not have perinatal loss but had repeated sex selective abortions. Interviewing these women was helpful to obtain rich data about the contexts of poor perinatal survival in the villages. The decision to choose them was based on information available to me through field notes and ongoing interviews during the fieldwork.

Generating a theory was not the purpose of this study. However, as Marshall (1996) argues, a form of theoretical sampling strategy has been utilised based on researcher's reading of field notes and listening to audio files of interviews during the fieldwork. Yet, this study did not follow the simultaneous coding as described in grounded theory approach.

3.4.2   Participants in the Study and Their Size

As already discussed in Section 3.4.1, unlike quantitative studies, a pre-determined sample size is not considered a key concern in qualitative studies. The logic and power behind selecting a sample is to understand a phenomenon (Patton, 2015). Therefore, a researcher is mainly concerned to select information-rich participants, the ones who can inform any emerging questions related to research question and objectives under investigation. The purpose of a study and the potential of accessing information-rich cases determine the size of sample.

> There are no rules for sample size in qualitative inquiry. Sample size depends on what you want to know, the purpose of the inquiry, what's at stake, what will be useful, what will have credibility, and what can be done with available time and resources (Patton, 2015, p. 311).

Marshall (1996, p. 523) also describes size to be dictated by whether a research question has been adequately addressed: "An appropriate sample size for a qualitative study is one that adequately answers the research question". Particularly, in public health, due to the complex research design of qualitative research, Ulin et al. (2012) demands that many groups and individuals are needed to answer a research question.

> In public health, however, most research design is not that simple. Generally, you collect data from as many groups or individuals as necessary to answer the research questions (Ulin et al., 2012, p. 55).

Appropriate size including participant recruitment strategy emerges during the fieldwork. Besides the above mentioned recruitment criteria, a sense of saturation (Brewer, 2000; Glaser & Strauss, 1967) also discussed above in Section 3.4.1 about the breadth and topic of this investigation—the poor perinatal survival, guided me to decide the number of the participants in this study. I conducted 42 interviews with women and their family members including their husbands, mothers-in-law and fathers-in-law from the two villages. In the interview setting, as long as the family members were present at home, they naturally tended to add their comments during the women's interviews. These added comments were found appropriate to understand their perspectives to explore in depth about the perinatal death that occurred in their family. After interviews with women, family members, mainly the husband and mother-in-law, considered appropriate to explore further information about the perinatal death, were contacted later even if they were not present during the interviews with women. Table 3.2 summarises different participant groups recruited in this study and their key features. To elaborate further, the participants were selected purposively to understand socio-cultural and health care contexts of the problem under study—poor perinatal survival in the mountain villages.

As Ulin et al. (2012) suggest, a range of participants (Table 3.2), were recruited to allow sufficient breadth and depth of the contexts of the poor perinatal survival. As well as the interviews with women and their family members, this study also comprised interviews with health service providers, and stakeholders including a non-governmental staff, a teacher and journalists (Table

3.2, Section 3.4.3). Interviewing the range of participants has provided multiple perspectives and helped to triangulate data source (Konecki, 2008) to provide a rich data set and abundant description in this study.

Table 3.2 Types of participants recruited, and their key features

Participants	Number of Interviews	Details
Women and family members	42	• 35 interviews targeting mothers with additional comments from husband, fathers-in-law, and mothers-in-law were available • 6 interviews with husbands with added comments from women • 1 interview with only mother-in-law
Health service providers	11	• 9 Skilled Birth Attendants (SBAs) • 1 Auxiliary Health Worker • 1 non-SBA trained Auxiliary Nurse Midwife
Female Community Health Volunteers (FCHVs)	2	• 1 FCHV had lost her newborn grandchild in the last two years, and • 1 FCHV who had given birth during the last year
Stakeholders	4	• 1 teacher, 2 local journalists, 1 Non-Governmental Organization officer
Support staff at health institutions	2	• 1 support staff from a community birthing centre, and 1 from the local health facility in the village
Traditional healer	1	• The locally popular head of traditional healers who treats the largest number of children across the villages

Source: Fieldwork, 2015

Inclusion of the diverse group of participants has provided a deeper understanding of the context of poor perinatal survival rather than measuring their differences; which is also one of the highly effective aspects of qualitative study (Ritchie et al., 2013). In a qualitative methodological approach, the choice of the sampling strategy also emerges, and researchers take advantage of any unforeseen opportunities in the field during the course of fieldwork (Ritchie et al., 2013; Van Olmen et al., 2012). Study units are selected to gain understanding of the nature, form of phenomenon, unpack meanings, ideas and explanations.

Besides those initially sampled, I interviewed stakeholders such as a teacher as the local knowledgeable person to understand the common occurrence of child marriage in the villages, traditional healers to understand *Dewata* (God) in seeking care for mother and baby, and a stakeholder working in health and local governance on behalf of an international agency. I also had informal chats with officials at the district's Women Development Office, International Non-Governmental Organisations (I/NGOs) working in the field of maternal and child health, and individuals responsible for social protection, child marriage prevention at local government and NGOs in order to understand their views of care during pregnancy, during and after birth and related perinatal deaths. Notes were taken of these chats and they have been used as supplemental data in this study. Study units are selected to represent and symbolise the features of relevance to the investigation; the sample is as diverse as possible within the boundaries of a defined population (Ritchie et al., 2013), which for this thesis was the women and families living in the remote mountain villages.

The decision regarding appropriate sample size was challenging and the idea of saturation was not straightforward. I frequently experienced a dilemma to draw a line at what depth and breadth and how many emerging themes and sub-themes within the topic of investigation saturation applies. Different intricacies and complexities related to this topic (perinatal survival) in itself, and my public health background (which is often a multidisciplinary and a pragmatic approach) also subtly influenced translating the idea of the principle of saturation in the fieldwork.

Additional invitations to the interview participants were stopped when I felt that the generated data were enough to understand poor perinatal survival in the villages. This was based on observation in the field, listening to audio records and the field notes. A sense of saturation regarding women and their family members' perspectives about their babies' deaths was felt after the first 37 interviews with diverse groups of women, their husbands and families from both lower and upper caste, and *Lama* and *Khas* ethnic backgrounds. Additional interviews showed that no new insights were emerging regarding the topic of this study. Although I did not simultaneously carry out data collection and coding, going through interview records, field notes and reflecting back to the main purpose and key objectives of this study helped him to sense a level of saturation in this study.

3.4.3   Study Site and Participant Recruitment Process

Villages from Mugu district were selected for this study purpose. Mugu is a remote mountain district in Nepal's Karnali region, the most under-developed mountainous region reported with high child mortality, poor service uptake and lowest human development index in the country.

Village selection

Two study villages[5] were selected on the basis of population size, accessibility to participants, ethnic and cultural compositions, and health care. In the first village, these were mostly the people of the *Khas* background who followed Hinduism. In the second village, most were *Lama* people who followed Buddhism. This was guided by a review of records about perinatal mortality, and consultations with the staff from the District Health Office (DHO). Suggestions were also sought from officials of local government (District Development Committee, Women Development Office), and NGOs working in the field of maternal and child health in the district. Both villages were reported to have health facilities with birthing units to provide 24-hour childbirth services. During initial days, I spent most of the time at the DHO reviewing the reports and records of antenatal, childbirth, postnatal contacts and mortality records. I also participated in DHO's meetings and training events related to maternity and newborn care. At this time, I also interviewed the acting chief of the DHO, the public health nurse and other hospital nurses. These interviews were part of the data collection in this study. The initial visits and interviews helped to increase knowledge about the potential study villages and the possibility of accessing women. In consultation with the health workers and after reviewing their reports, I found only one neonatal death in the first village and four neonatal deaths recorded in the second village. No record of even a single stillbirth was identified in the health facilities from both villages. These meetings and consultations were necessary for extending my courtesy at the district and health facilities in the villages. This also facilitated the recruitment of health service providers and other stakeholders who could be interviewed in order to understand the contexts of perinatal deaths in the villages.

Recruitment of gatekeepers

I utilised local Female Community Health Volunteers (FCHVs), a social mobiliser and a health worker as gatekeepers to facilitate participant recruitment in this study. The social mobiliser was a woman facilitator of the local women's saving and credit co-operative. As Devers and Frankel (2000) have described, utilising the gatekeepers as recruiters created trust in the villages, and made their accessibility far easier than was initially expected.

- First village: Seven FCHVs
- Second village: Four FCHVs, one social mobiliser and one local health worker

After the selection of villages, contacts were made simultaneously with the persons in charge and other staff of the local health facilities (auxiliary nurses, auxiliary health workers and peon), local health facility committee members and NGOs working in the villages. I briefed them about the study and requested their support to connect him with the village FCHVs. I organised an FCHV

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[5] Considering the length of this chapter, the villages have been described in Chapter Four, Section 4.2 as a part of the study field context.

meeting to explain the purpose of this study at a health facility meeting. However, getting all FCHVs from the villages to their respective health institutions became impossible. Everyone was busy with their own domestic work. In consultation with the local health facility staff, I recruited an active FCHV in the first village, and a local female social mobiliser and a local health worker in the second village to support as active gatekeepers and to facilitate meetings with the other FCHVs in the villages. With the help of these three active gatekeepers, I individually met other available FCHVs in both villages. Thus I was able to have a total of seven FCHVs in the first and four FCHVs in the second village. Based on health facility records, there should have been 18 FCHVs, nine working in each small settlement area, locally called the 'ward' of a village. However, the remaining seven FCHVs were found inactive and absent during this fieldwork.

During the recruitment process, I met with each of the FCHVs individually in both villages. I also had a chance to review their record which did not have any written record of perinatal deaths. Finally, these FCHVs were utilised as gatekeepers to inform people throughout the villages about the study and the village women's willingness to participate in the study. In Nepal's community health system, FCHVs are the community level cadres who are close to, and are generally trusted and respected by women and families in the villages. It was culturally appropriate to utilise FCHVs for recruiting participants as initially stated during the ethics application to obtain ethical approval for this study.

In the second village, in addition to the available FCHVs it was felt that a female social mobiliser and a local male health worker would be appropriate as active gatekeepers as they were seen to be more trusted by the locals. Many FCHVs in the village were inactive and some were absent at the time of the study. Locals trusted the female social mobiliser and the local male health worker more than some FCHVs and auxiliary nurses. In addition, the local health worker, though not belonging to the *Lama* community, was fluent in the local language and was well respected and trusted by the village women. I observed that more women felt at ease in sharing their experiences with the female social mobiliser and the local male health worker than with many FCHVs. During his stay at the local health institution, I noticed that though he was not a SBA, women in the village were friendly with him and trusted him.

Utilisation of the FCHVs, the social mobiliser and local health worker made the invitations more feasible in terms of informing potential women throughout the villages if they wished to participate in this study. It also provided women with a chance to show their willingness through any of the FCHVs or social mobiliser or the local health worker as they preferred.

The FCHVs, social mobiliser and health worker were briefed about the study, the potential benefits and possible disadvantages of participating in the study, and were provided with a letter of introduction and a plain language consent form (Appendix 1.1 & 1.2) translated into Nepali language. The gatekeepers had opportunities to meet and ask women while going to the forest,

farm, to fetch water and any woman attending health institutions about their willingness to participate in the study. The gatekeepers were asked to verbally invite any woman who was willing to share her experience and talk about neonatal death with me.

Recruitment of participants

The recruitment of participants commenced by consulting with DHO, identifying gatekeepers to approach and brief participants about the study and to seek their consent to participate in the study (Figure 3.1). Additionally, some participants were selected by a snowball technique via participants' contact. Snowballing is a chain referral sampling in which a participant refers another participant with characteristics which are of research interest (Biernacki & Waldorf, 1981; Patton, 2015). Snowballing is commonly used in qualitative sociological (Biernacki & Waldorf, 1981) and nursing research (Sadler, Lee, Lim, & Fullerton, 2010), particularly when a study focuses on sensitive issues, private matters or deviant behaviour.
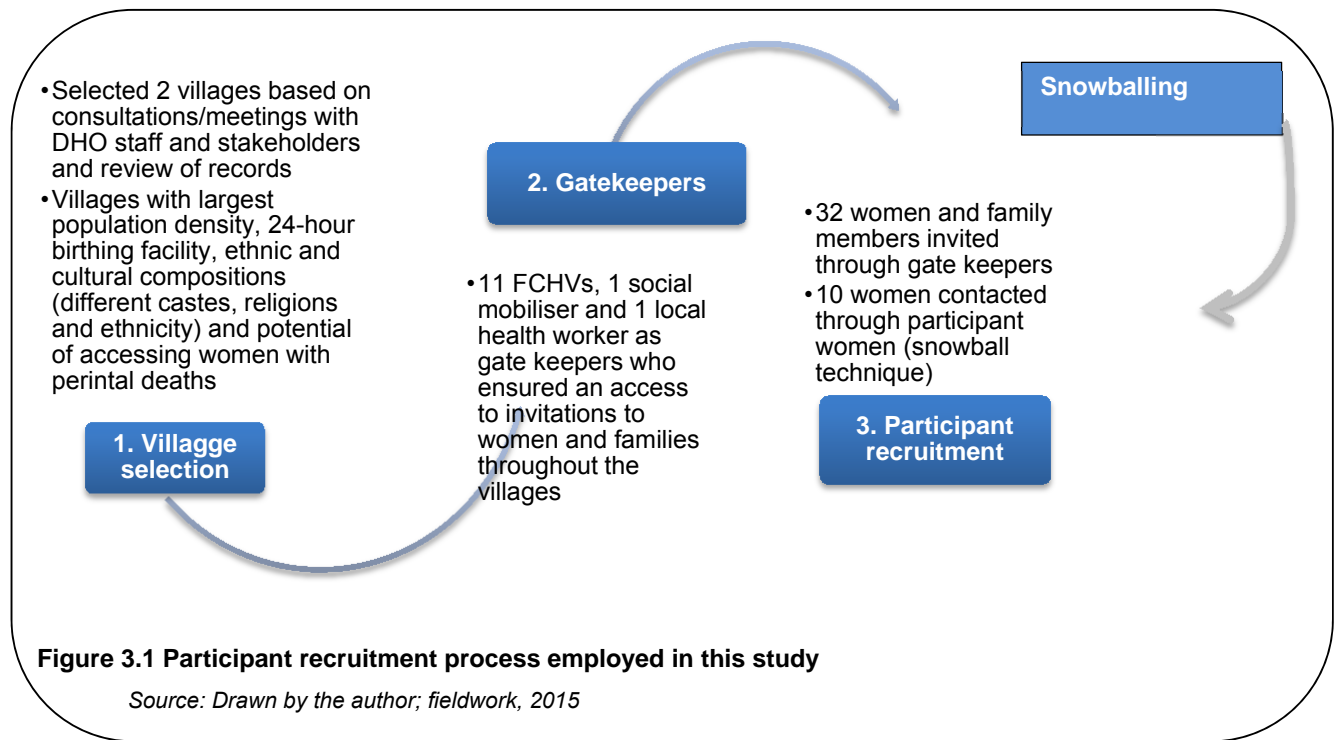
Figure 3.1 Participant recruitment process employed in this study

Source: Drawn by the author; fieldwork, 2015

First, an initial list of potential women was prepared. These were the women who had self-reported their perinatal deaths to the gatekeepers (the FCHVs, the local female social mobiliser and the local health worker). Their permission to participate in the study was confirmed with an informed written consent when I subsequently contacted them. Snowballing technique resulted in the recruitment of ten more women in the first village. Potential participants who were identified by the interviewees during their interviews (snowball technique) were approached by me after they agreed to be contacted by me. I requested the initial group of participating women to first seek

verbal consent from the women who they suggested, to participate in the study and to help me locate their houses if they agreed to be contacted by him.

I received from these gatekeepers, the names and contacts of women experiencing perinatal deaths and willing to be interviewed. There were some women who reported only toddler's deaths and deaths of under-five children but older than early infants and so were excluded from the study. The only women asked to participate in the study were those who were identified by the gatekeepers and the initial group of participants (snowball), and were found appropriate to the study purpose after I reviewed their cases.

3.5 Data Collection Techniques and Procedure

3.5.1 Overview of Data Need and Methods Used

The study objective of understanding the socio-cultural and health care contexts of perinatal survival and the theoretical perspectives on social constructionism and critical theory demand techniques through which in-depth complex data can be generated in natural settings. The natural setting comprised qualitative interviews of women and families taken while in their everyday living context in the study villages. The study methods were required to be less obtrusive to inquire into the experiences of women and their family members who have lost their babies. The following research methods were used (also illustrated in Figure 3.2):

- Qualitative in-depth interviews; interviews were utilised as the key research methods to generate data from the field;
- Review of policies relevant to perinatal survival in Nepal;
- Field notes on observation in communities, households and health institutions, the notes from informal chats with stakeholders and community participants; and
- Field photos which have been utilised to supplement the interview data in this study.

Figure 3.2 An overview of key features related to data utilised, and techniques to generate data in the study; *Source: Drawn by the author; fieldwork, 2015*
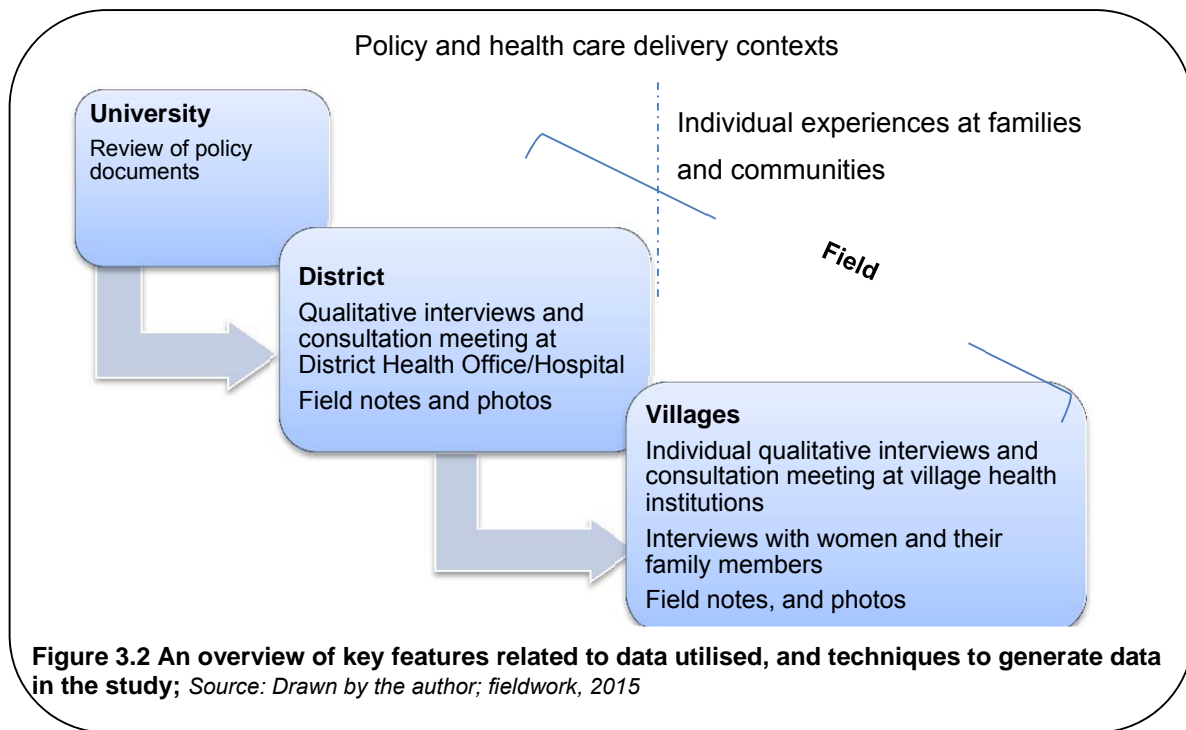
The following section details each of the methods used in the study.

3.5.2   Document Review

Prior to commencing the fieldwork and data collection (Figure 3.2), a review of national policy documents covering the period from 2000 to 2015 was undertaken. Six policy documents were found current and crucial in relation to perinatal survival at primary health care settings in Nepal.

The documents included:

- National Neonatal Health Strategy 2004 (MOHP, 2004b);
- National Policy on Skilled Birth Attendants, 2006 (Supplementary to Safe Motherhood Policy, 1998) (MOHP, 2006a);
- National Safe Motherhood and Newborn Health Long Term Plan (2006-2017) (MOHP, 2006b);
- Mother's Protection Programme-Implementation Guideline, 2013 (revision on Safe Delivery Incentive Guideline, 2007 and 2009) (MOHP, 2013);
- Maternal and Perinatal Death Surveillance and Response (MPDSR) Guideline, 2014 (MOHP, 2014); and
- Community Based Integrated Management of Neonatal and Childhood Illness (Programme Management Module, 2015) (DoHS, 2015).

The objective of the review was to understand the policy context within which perinatal care programmes are implemented. The review also enabled me to compare and contrast policy priorities with the views of women, communities and health care staff on the ground. The documents were synthesised using qualitative content analysis technique as Hsieh and Shannon (2005) have suggested, and followed an adapted framework (box 5.1, Chapter Five) from Newman et al. (2006b) and Walt and Gilson (1994). Hsieh and Shannon described a directed approach of qualitative content analysis in which prior themes direct a document review process. The key prior themes in the policy analysis were document formulation, values, strategies and outcomes which were clearly outlined by Newman and colleagues in their framework. Walt and Gilson suggest a triangular approach of policy analysis that includes context, technical content, and the process of policy formulation and actors in formulation and implementation. The detail of the document review is described in Chapter Five. This review focussed on identifying the strategies, underpinning values, and nature and extent of health care services to improve poor perinatal survival in Nepal, and in the remote mountainous region of the country. This policy review also prepared me for interviewing health service providers and other stakeholders, particularly to explore their views about the influence and impact of currently effective policies in the context of the perinatal survival in the villages. Comprehensive understanding of the policy environment was useful in examining the translation of policies into practice and potential enablers and constraints in a local health systems context.

3.5.3   Qualitative Interviews

Qualitative interviews facilitate in-depth understanding of a topic to be investigated (Patton, 2015; Ritchie et al., 2013). A qualitative interview helps to explore personal experience, history and a complex and detailed subjective matter which might be confidential and sensitive as well (Ritchie et al., 2013), therefore making it appropriate to investigate the complexities surrounding the topic in this study. An individual interview is considered an appropriate approach to collect data if there is an issue of power conflict or status, and also, when the informant does not feel confident to narrate opinions and ideas in a group situation. However, in the conversations with the women in the villages, comments from fathers, mothers-in-law and fathers-in-law became unavoidable. Conversations in some interviews were dominated by family members' experiences. The inability of the participating women to relate their own experiences and perceptions is a function of the power play within a family and reflects the helplessness of the women giving birth. Even if the experiences and perceptions in some interviews do not necessarily only reflect those of the women, they are still important and valid in that they reflect the context in which pregnancies and child births occur in these villages.

Prior to conducting the fieldwork, it was planned to have focus group discussions with the participating women, their husbands and FCHVs, but these were not considered appropriate and necessary as the situation unfolded in the field. During the early phase of the fieldwork, I invited

young fathers for a group discussion but they were reluctant and felt less comfortable to participate in a group setting. Rather, they preferred one on one interviews. Considering the busy schedules of the village women and FCHVs, inviting each member to a place at an agreeable given time to conduct group discussion was impracticable.

In doing qualitative interviews, Liamputtong (2007) describes that one must build a rapport with research participants and adapt to a real life situation. Moreover, Kvale and Brinkmann (2009) describe qualitative interviewing as closer to a craft where a researcher becomes the key instrument. An interview is not even reduced to a method unlike in survey interviews.

> We conclude that while survey interviewing may be adequately described as a method in a strict sense, qualitative research interviewing is closer to a craft. The personal skills and respect needed to practice qualitative research interviewing excellently cannot be reduced to methodological rules (Kvale and Brinkmann, 2009, p.84).

In describing interviewing as a craft, Kvale and Brinkmann (2009) have argued that an interviewer needs skills, knowledge of the study topic, and a situated judgement as a professional in an unfolding field context. Epistemologically, Kvale and Brinkmann (2009, p. 48) used metaphors to describe an interviewer "as a miner or as a traveller". While considering the interviewer as a miner: "Knowledge is understood as buried metal and the interviewer is a miner who unearths the valuable metal…", and the interviewer as a traveller, s/he "...walks along with the local inhabitants, asking questions and encouraging them to tell their own stories of their lived world". In this study, I aimed to uncover taken for granted values and customs, which is also congruent with the theoretical perspectives discussed earlier in this thesis.

The interviews with women and their family members explored their views and experiences surrounding the perinatal deaths in their families. The interview focused on the questions covering the what (for example, sickness and perinatal death), when, where, why and how of the events (sickness, perinatal death). Rather than approaching the interview as a tool to what Kvale and Brinkmann (2009) describes with the miner's metaphor considering knowledge as 'out there' waiting to be discovered, each unfolding interview was considered to reveal new realities about poor perinatal survival in the villages. In this study, some women shared their stories more naturally, whereas others, especially young mothers, were unable to channel their thoughts. In such instances, I further probed and provided examples of other women's experiences to remind and encourage participants to share their experience and views.

Researcher's gender and its impact on interviews with female participants

I was aware that as a male researcher, it could be problematic to interview women and their families on topics such as pregnancy, childbirth and baby losses, which are generally perceived as sensitive issues (Liamputtong, 2007, 2010). Being male, it was certainly more comfortable for me to gather the views of fathers and fathers-in-law. One of the noticeable differences that I noted

during my fieldwork is that I was able to have longer informal chats with fathers and fathers-in-law even after the formal interview sessions were completed. On the other hand, even though it was not as easy for me to be open with female participants, or to have long, post-interview informal chats with them for clarifications about topics raised at the formal interviews due to the short time at their disposal, I was able to gather from them sufficient and a thorough account of their pregnancy, childbirth and perinatal deaths (Chapter 6, 7, 8).

More specifically regarding the impact of gender (a male researcher interviewing female participants), I reflect that it all depends on how a researcher decides the topic of investigation (what led the researcher to choose the particular research area), the study community (how they perceive about the topic of investigation), role of gate keepers and the way study has been briefed during invitation, and the interviewing setting. Doing research on such sensitive topics by a male researcher might create hesitancy around, or can become not a natural occurrence to a novice researcher without prior fieldwork experience. I had prior fieldwork experience of more than 7 years in Nepal, mostly worked in areas of maternal and child health with women in communities, female community health volunteers and health service providers. I was motivated to conduct this study with my own prior observations of the women and children's poor health, sickness and deaths during my previous work in Nepal, and in my kinship. I believe my 7 years of experience working in communities made me sufficiently aware of the plight of the poor women and their children in rural and disadvantaged communities, and this compelled me to know more about them, and made me rather sensitive about their problem. This helped me in operating beyond the normally considered assumptions about what a sensitive issue is against their suffering. Regarding the study community, I was aware that issues such as pregnancy loss/perinatal deaths were rather common in the study regions and were taken ordinarily.

Participants were informed that I was a previous health worker with prior experience of working with women in their neighbouring district and had seen perinatal deaths with several other women during his professional life, including in his own family and kinship. My personal background and work experience made it easier to build rapport with participants, conduct interviews and explore information about a sensitive topic such as pregnancy, childbirth and perinatal deaths. This helped participant to clearly understand me as a previous health service provider—not as any 'male' willing to know about their pregnancy, birth and child deaths without purpose. When the interview was around what led to their babies' death--there was not much an impact of my gender in inquiring it and they frankly shared what had happened. I clearly briefed them that the purpose of interviewing them about pregnancy and childbirth was to have their natural experience so that it might help to further reduce child deaths in their communities and for women in other communities. Although it could be context specific, the women and their families were quite happy and wanted me to stay longer and were willing to share their experiences. I allowed interview participants to share their stories by being a listener, remaining as informal as possible. In the local context of the

villages, a formal interaction creates a hierarchy between participants and a researcher (interviewer). To avoid any formality in the interaction, I made all efforts to create as informal and friendly an interview-environment as possible. Creating interview environment this way became useful and helped in natural occurrence of the interview.

Another strategy which created trust among female participants, and thereby reduced the potential impact of a male researcher conducting the interview was the use of gate keepers. As already described (section 3.4.3), I utilised female community health volunteers, locally active woman and a trusted health service provider in recruiting the village women.

Interview process—the women and family members

Interviews were conducted with 42 women and their family members as outlined in Table 3.2, who agreed and were available during the fieldwork period. The majority of the women were interviewed at their homes. Others were interviewed at their work places, on their way to their work places, or while returning home from work. The participants' response while working, going to work, or returning from work assured a free and frank exchange of views and experiences. However, it was realised that interviewing at home was more comfortable for the women and their families, particularly in cases where husbands were not working away from the villages, or who were in a joint family with mothers-in-law and fathers-in-law. In the first village, all interviews were conducted in Nepali language by me. In the second village where *Lama* people speak *Bhotebhasa* (their local language), interviews were conducted in *Bhotebhasa* with the help of a female social mobiliser and a local health worker who were utilised as gatekeepers in recruiting the participants. The female social mobiliser and local health worker were from the same *Lama* village and knew both Nepali and *Bhotebhasa*. They translated for me during the interviews with the *Lama* women and their families, and were familiarised about the purpose of the study and the importance of participants' own opinions and experiences in qualitative research. I advised them to exactly translate interview questions and their responses as and when they were asked during the interview by me and not to add their interpretation during the translation. Although the *Lama* people understand Nepali language to a certain extent, it was difficult for them to converse naturally in Nepali. The women found it more difficult than the men because the men were more outgoing and had opportunities to interact with people from the *Khas* community who spoke in Nepali.

The views and experiences of each woman's family members, usually husbands, mothers-in-law and fathers-in-law were also included when they provided comments during the conversations with the women. None of the family members were prevented from adding their experiences during the interviews with the women, or afterwards as long as they were present at home. For those who were not present at home, I revisited and asked their permission to add their experiences in the interview when appropriate. Added views from family members have been counted as a single interview within a woman's interview. Family members' views about the perinatal deaths were

crucial as they provided further detailed information. it was also useful to compare different perspectives similar to what Rusman et al. (1999) describe in their study using the 'Rashomon technique' that brings multiple subjective opinions about a single infant death. Interviewing at home was found culturally more acceptable than interviewing at other places. Rather than doing a separate interview away from home, the home setting together with family members comforted women and their families, and it was culturally respectful in the context of these villages.

Each interview began with an informal chat about their families, their livelihood and their children. Then, I entered conversation with simple general questions related to their marriage, pregnancy and childbirth experiences. I had prepared separate interview guides, one for each participant group: health service providers, volunteers, women, and family members. The interview guides (Appendix 3) were piloted with four people (two women and two service providers) in a neighbouring district and revisions were made accordingly. Except the informal chats with stakeholders and service providers during the field stay, interviews were recorded when participants agreed to be recorded. In fact, all women participants were willing to be recorded and photographed. They found it an interesting experience to hear their recorded voices and to see their photos.

Participants were given the opportunity to provide further comments or ask additional questions after the interview, if they wish to. During the researcher's stay in the village, some community members (not eligible as study participants) expressed their interest to be interviewed around the topic. Their interest to participate in the study was met through informal meetings with them and courtesy visits to their houses by the researcher. These conversations, although not considered as study data, assisted me to better understand the socio-cultural context of the study villages.

Interview process—service providers and other stakeholders

I conducted 11 interviews with health service providers at their respective work place; and five with stakeholders, two with female community health volunteers and a traditional healer at their homes. The interviews with health service providers, including volunteers, were focused on their views and experience regarding factors behind continuing perinatal deaths in the communities, and any constraints and enablers they experienced in providing health care at health institutions, local community out-reach and at home. The interviews also focussed on understanding the influence of national policies, strategies and their implementation at local contexts which impacted on the health care for perinatal survival at the villages.

On average, the majority of the interviews were 20 to 30 minutes long. However, a few interviews went up to one hour or even longer. Generally, the interviews with stakeholders and health service providers took longer. Except during the informal chats, I took notes after the interview session as it was felt that taking notes during the interview interrupted the natural flow of the conversation.

3.5.4 Field Notes, Observation and Photography

Descriptive as well as reflective notes were taken after meetings and consultation at health institutions, informal chats with service providers, and interviews with women and their family members. Notes were also taken regarding the basic demographic characteristics of the participants, key local terminologies which emerged during the interview and post interview chats with participants, informal chats with other people, reflection on interviews, and suggestions for the next interviews. The photography included photos of the material context such as roads, birthing sites, and care for the babies such as clothing, sleeping, feeding in the communities.

Note taking was important especially to capture the researcher's concurrent thoughts after each interview. These notes were realised to be important to this study because part of data processing commenced during and straight after the interview when the setting was live and fresh. The notes taken became essential in interpreting how locally used terms, such as *Dewata, Gotha*, *Pakhalajane* were related to perinatal survival in the villages.

The observation included events such as the training of health providers and health volunteers, review workshops of health institutions, and seminars related to maternity and neonatal care, which were held during the fieldwork period. It also included observation of general infrastructure and birthing rooms in hospital and local health facilities; and the interviewees' housing to identify factors which impacted on perinatal survival (for example, the birthing place at home, presence of smoke/air pollution, cleanliness, access to clean water, warmth etc.). The fieldwork provided an opportunity to visit hospital and village health institutions, to observe their daily activities, the records and reports, and chances to interact with service providers during and after office hours. Since I stayed in villages at the households of the traditional healers, health workers, FCHVs and the members of local health management committee, this gave an opportunity to observe their everyday lives and living. It added an opportunity to interact more about care of babies, care of mothers during pregnancy, birth and postpartum period that have implications in perinatal survival. It helped me to reflect on the daily contexts of what was discussed during the interviews and to ask questions which otherwise may not be considered.

3.6 Data Processing and Analysis

From the beginning of this study, I was aware that the qualitative methodological design is an emergent and an iterative process (Denzin & Lincoln, 2011; Maxwell, 2013; Silverman, 2013). This meant that the research process is not viewed linearly as in positivists' quantitative strategy. Miles, Huberman, and Saldana (2014) and Silverman (2013) suggest that the boundary between data collection and analysis in qualitative research becomes less evident. The analysis therefore does not become a unique particular step as viewed in the positivist's research approach. Rather, it becomes a continuous process, emerging more vividly from the researcher's entry into fieldwork,

learning from each participant, writing analytical notes, and going back again to collect data as required, as experienced in this study. During data analysis, I repeatedly went back and forth to examine the epistemological commitments of the chosen theoretical concepts (Chapter Two, Section 2.5.3), and the research question and objectives. Every bit of data was processed with repeated questions as to whether and how the data collected answered the key research question, socio-cultural and health care contexts of poor perinatal survival.

While constructing meaning from the data, I continuously raised questions around additional aspects that the data could unfold in illuminating socio-cultural and health system contexts and thereby contributing to the prevention of persistent perinatal deaths. This process was helpful in drawing concepts from the data, and to discuss their relevance in this study. The moments of note taking during and after the interviews, playing back the audio records and the transcribing and coding process, brought me back to the lives of the research participants, the young women and their families who had gone through persistent loss of their babies. The vivid mental picture of participants helped me to crosscheck whether what has been written about them is actually representing their voices. This was also a continuous reminder to think through and investigate underlying forces, which were deciding apparent behaviours and attitudes related to perinatal deaths in the villages. This intention in this study facilitated not just note taking in the field, but understanding further about what had permeated through the common and apparent descriptions of the ongoing perinatal deaths in the villages.

3.6.1   Methods of qualitative data analysis

Before deciding one particular method of data analysis, I read through different approaches of qualitative analysis before the fieldwork, and also went back again to this after the fieldwork.

Grounded theory approach

In grounded theory approach (Creswell, 2013; Glaser & Strauss, 2017; Ralph, Birks, & Chapman, 2015; Starks & Trinidad, 2007), it is unique that data collection and analysis is a simultaneous process—without a boundary between data collection and analysis. Themes emerge only from raw data on the ground. The sampling is theoretical—decision on each next participant to be interviewed and the size of participants is judged based on the analysis of previously collected data. Grounded theory approach does not even require a previous literature review, and considers the literature review itself as a data set for coding. Grounded theory is useful when little is known about the phenomenon of interest, and the main purpose is to generate theory.

Interpretive phenomenological approach

This approach brings its own frame to analysis, considering an essence—the structure and texture of the lived experiences (Biggerstaff & Thompson, 2008; Creswell, 2013; Holloway & Todres, 2003; Patton, 2015; Starks & Trinidad, 2007). Knowledge claims in phenomenological analysis are made

cautiously, not as causes or explanations, they are often made as 'seems so and so' about features of the lived experience. Analysis emphasises the primacy of the experience lived out by participants no matter how much an experience is prefigured by the political, cultural and language contexts. It is not limited in accepting knowledge production as just social construction, it demands bracketing of a researcher's background, therefore having an inclination towards the objective view of a nature of reality.

Content analysis

Content analysis is attached more towards quantitative orientation, counting text or themes in a data set than describing and understanding a phenomenon qualitatively (Joffe & Yardley, 2004; Patton, 2015; Starks & Trinidad, 2007).

Thematic analysis, the analytical technique chosen in this study

Thematic analysis is an approach which extracts themes from a complex set of data in diverse contexts (Alhojailan, 2012; Attride-Stirling, 2001; Boyatzis, 1998; Braun & Clarke, 2006; Fereday & Muir-Cochrane, 2006; Joffe & Yardley, 2004; Miles et al., 2014) as with the bulk of data from diverse participants in this thesis. Braun and Clarke explained clearly the process of undertaking thematic analysis in six key phases, providing me with confidence to navigate across these phases. The phases are:

- Phase 1, Familiarising oneself with the data;
- Phase 2, Generating initial codes;
- Phase 3, Searching for themes;
- Phase 4, Reviewing themes;
- Phase 5, Defining and naming themes; and
- Phase 6, Producing a report.

After several readings of their analysis technique, this was identified as a workable analytical strategy in translating raw data through the phases to the production of the thesis.

In addition, in choosing thematic analysis, I became aware that thematic analysis does not prevent the application of the epistemological commitments. Braun and Clarke (2006) discuss two different kinds of analytical methods—one group of methods is tied to their theoretical and epistemological position and has relatively limited variability in how the method is applied, such as conversation analysis and interpretive phenomenological analysis. This also comprises methods with different manifestations from within the broad theoretical framework such as grounded theory, narrative analysis and discourse analysis. Another group comprises those independent of theory and epistemology, and therefore could be applied to a range of theoretical approaches. Thematic analysis has this theoretical flexibility. In addition, thematic analysis moves beyond counting words

and phrases to understand both implicit as well as explicit ideas coming through the data (Guest, MacQueen, & Namey, 2011), which is an advantage over content analysis technique.

During the analysis, the social constructionist and a critical theoretical perspective provided insights into what was unfolding as a socially constructed concept and the underpinning social forces. As a constructionist, I assumed the reality of the poor perinatal survival in the study villages is a result of prior social agreements of individuals. This assumption guided how I produced knowledge from this study. As a critical position, I considered this not just as a medical truth, considered as an issue of injustice, and had motivation to explore social and cultural forces behind and give voice to the women and families from isolated mountain villages. This helped to continuously seek the underlying meanings of why certain kinds of statements have been made by the participants. As Braun and Clarke (2006) suggest, thematic analysis is not a method like grounded theory and interpretive phenomenological approach, and does not therefore bring a framework of doing research. This flexibility is a hallmark of thematic analysis where a researcher can choose his/her own theoretical lens and use thematic analysis as an analytical method. For novice researchers, both critical or constructivists, it provides a clearly defined procedure to analyse data, and is therefore more accessible. Yet, it is not without limitations.

The often cited limitations are about the lack of clear agreement in doing thematic analysis among researchers, and not necessarily telling researchers about distinctive techniques to identify themes, which may lead a researcher to choose a wrong theme, then the whole process becomes pointless (Bryman, 2008). Bryman also argued that unlike content and discourse analysis, thematic analysis does not have an identifiable heritage in the qualitative analytical approaches. Although flexibility is an advantage of the thematic analysis, Holloway and Todres (2003) reinforce the tension of maintaining flexibility and coherence as a central point in maintaining rigour. Considering such limitations, and also becoming aware of the lack of an appropriate analytical tool to facilitate analysis in qualitative research (Denzin and Lincoln, 2008; Huberman and Miles 1994, Lee and Fielding, 1996), it was realised that the clear step by step process of doing thematic analysis following Braun and Clarke (2006) provided a relative advantage in this study.

Thematic analysis involves identifying, analysing and reporting various themes from the research. Themes are the central organising concepts about data. In this study, these are the aspects within the data, which have revealed socio-cultural and health care contexts influencing perinatal deaths in the remote villages under study.

Producing themes involves an inductive (data driven) and theoretical (theory led) approach (Braun & Clarke, 2006), and the themes could be categorised at two levels: semantic and latent themes (Boyatzis, 1998). Under semantic theme, a researcher brings explicit and surface meaning. Under latent themes, a researcher seeks to find underlying ideas and conceptualisations. In this thesis, the ideas and concepts influencing women and their families' descriptions regarding perinatal

deaths are examined. The thematic analytical approach used remained more data driven. Yet, I acknowledge that the influence of priori knowledge cannot be ruled out during the analytical process. I felt influenced by knowledge from the previous literature and the research objectives. During the coding process, it was necessary to go back and forth to the research question and objectives. However, in doing so, attention was given not to miss any important ideas from the data by frequently revisiting, reading aloud and reading on screen, listening to the recordings, and reading the printed version of interview transcripts.

A brief reflection is provided on each phase of the thematic analysis (Braun & Clarke, 2006) about how I moved through the phases in doing thematic analysis in this study.

Phase 1, familiarising oneself with the data

Familiarising oneself with the data is fundamental to a robust qualitative analysis which Braun and Clarke (2006) consider as the 'bedrock' to the rest of the analysis. It emphasises a researcher's immersion into data. This suggests repeated and active reading of data to search for meaning and patterns; reading the entire data set at least once before coding; and taking the opportunity for note taking. The interview transcripts, notes of observations and informal chats, relevant documents at district and policy level and the field photos emerged as the foundation to this analysis. Activities such as replaying the audios, transcribing and translating interviews, note taking and planning subsequent interviews, photography and organising photos to make best use of them while supporting any analytic claims, were considered as ongoing strategies to familiarise me with the entire data set. While in the field, after each interview, the record was replayed, and notes were taken during and after hearing the audio recordings. This helped to prepare for each following interview.

The informal chats with local stakeholders and note taking became keys to reflect major ideas emerging in interviews. These became helpful to uncover meanings from the data. The informal chats became especially useful in exploring the meanings of local terms and practices which emerged during the interviews, such as *Chordat, Gotha or Raikosa, Taplagne, Lekhghar, Aulghar, Nal and Hadnepadne, Pakhalajane, Karma, Bhagya, Lekhanta, Banlagne, Mojhlagne etc.* I had to observe, identify local experts for short informal interactions, and to approach additional stakeholders and faith healers to understand these terms and their meanings in everyday living contexts. Likewise, photos were taken of the contexts that visually portray the situation of health care institutions, the places where women give birth, the cultural practices of caring for the baby after birth such as clothing, putting the baby to sleep, the local medicines and the treatment sought for babies during sickness, the housing—space inside and the use of ladders. Such photos also revealed aspects of the day to day living of women in the villages.

Transcribing: Braun and Clarke (2006) focus on the use of transcribing as an interpretive act, rather than a mere mechanical task. This to me meant not merely a task of converting audio records into text files, but also an activity to explore different aspects of the phenomenon of interest, which is about the context of perinatal survival as participants described in their stories. The interviews could not be transcribed while in the field due to remoteness of the villages, irregular and interrupted electricity in the first village and total lack of supply in the second village. Transcribing became an opportunity to further understand the depth of the participants' stories, and I myself undertook all the transcribing and translating. As Braun and Clarke (2006) suggest, it is a good idea to start taking notes, or marking ideas for coding while transcribing. Therefore, a memo file was created during transcribing and notes of each of the interviews during this translation and transcribing phase were taken. As the interviews were conducted in Nepali language in the first village and in *Bhotebhasa* with *Lama* people in the second village, the tape recordings were simultaneously translated and transcribed into English language. This method was successfully used by other researchers such as Kaphle (2012) and Gurung (2016) and was considered by me as well as discussed by Filep (2009) and Temple and Young (2004). Transcribing also helped to simultaneously examine the meaning and see patterns of what was interesting coming across the cases.

Six random transcripts were sent to five bilingual (Nepali and English) experts to check the consistency in transcriptions and translations into English language. Three of these five experts were current PhD students at Flinders University, one was research associate at Flinders and another was a past PhD student from Flinders University. This connection made it relatively easier to access these scholars and to ask them to check the translations. There were few expression errors, and inconsistency in exact translation of some local Nepali terms, which were then double-checked in the rest of the transcripts and also ensured no loss of contextual meaning of the terms. Otherwise, the translations were found to capture the meaning of what participants had shared. After completing the transcription and uploading them to NVivo (Version 10.00), a copy of all transcripts was printed. This was done to reduce reliance on screen reading, and it also greatly helped to go through the printed copy of the transcripts.

Phase 2, generating initial codes

Phase 2 describes code as a feature of data and coding as a process which could be facilitated manually or by a computer programme (Braun & Clarke, 2006). During this process, the authors emphasise giving full and equal attention to each data item, code for as many possible themes/patterns and 'inclusive coding' of extracts of data. By 'inclusive coding', they recommended including surrounding text so that the meaning is not lost. This phase was seen as the most challenging to initiate an appropriate coding structure. Referring back to the research aim, question and objectives (Chapter One, Section 1.5), and the literature and theoretical perspectives (Chapter Two, Section 2.5.3) assisted me to make a sense of what I would expect to see through the data.

At this stage, however, I was constantly aware of not forcing data to prior themes that provided a direction as an initial coding framework.

Coding of each transcript was undertaken following a full reading of the transcript on screen as well as the printed copy. This assured a reduced chance of missing an overall understanding of key emerging concepts from each interview. It was realised that reading through the printed copy also helped to catch some ideas missed during screen reading, and it also made reading active and engaging. This was helpful to understand the meaning in its entirety as Bradley, Curry, and Devers (2007) described it as effective to understand meaning and contexts without losing connections between concepts. Table 3.3 shows an example of data extract and codes.

Table 3.3 Example of data extract and coding

Data extracts	Coded as
If the baby's cord is cut with the small stick used to bundle the lamb's wool *(Bhedako Unkatne Lathhi)*, the baby's umbilicus won't be infected. And, they preserve the baby's cord once it falls off, and later use it as medicine for any blisters around baby's mouth and also during cough and cold.	Cord cutting Care during illness
… I called a *Dhami* there; he is younger than I am. I took his hand and requested him to come to help daughter-in-law. He came and started invoking God *(Dewata Paturne)*, shaking his whole body and inquiring to know what had happened. Then he said, 'your dead neighbour has become a hungry ghost *(Muiyalagne).* He requires sacrifice of two big chickens. After this, she is going to give birth to a son'. She will give birth by tomorrow in the morning. You can have your food and sleep now.' Then I took 100 rupees (about 1.5 AUD) from my pocket and gave it to him. I also committed that I will offer these two big chickens. Then, we went to *Deuda* (singing and dancing) again. Like he said, it was a baby boy and she gave birth the next morning. *Kanchho* (father) was happy and we distributed cigarettes and biscuits to other people. This was the truth from God *(Dewata), Dhami* predicted it a baby boy, and yes it came true.	*Dewata* (God) at childbirth Faith healer at birth Hungry spirit/ghost *(Muiyalagne)* Men's role Son preference (baby boy preference)

Source: Based on coding of the interview data

Initial coding framework: Initial data coding commenced manually on three transcripts and marginal codes were assigned to interesting data segments on the printed copies. The codes developed from this process were cross checked with three other researchers who were supervisors, and disagreements were discussed in supervisory meetings. During this stage, large categories extracted from the study aims and objectives (Chapter One, Section 1.5) and the literature (Chapter Two) such as 'health care delivery', 'socio-cultural and behavioural aspect', 'broader policy and politics' were developed as initial parent nodes in NVivo to help begin and organise the analytical process. This gave an initial coding framework (Appendix 7). While this initial coding framework assisted in directing the analysis process, due attention was given to ensure inductive process grounded on data. The coding framework was then built in NVivo software (version 10:00). Coding of the three initial transcriptions was redone using NVivo. Codes with similar patterns were merged.

Coding continued with additional transcripts. During this process, I started feeling a sense of being controlled due to the categories of the initial coding framework, and reminded myself to continue coding being more grounded on the data. The coding was continued until the completion of all

interview transcripts and field notes. At this stage, the child nodes in NVivo were descriptive themes that facilitated reading through and comparing the coded excerpts in each of the several nodes, and the source code, thus evolving into the third phase of searching key sub-themes and themes across the entire data. It was realised that this stage helped to examine the initial semantic patterns of the data, and prepared me to collate codes as per conceptual homogeneity, described in Phase 3.

Phase 3, searching for themes

In this phase, emphasis is given on visual representations of data through mind maps and tables; analysing data at broader level—sorting out codes to generate themes and reading about the codes themselves; and the relationships across codes, themes and sub-themes (Braun & Clarke, 2006).

I reviewed each node: parent, child and sub-nodes, searching for potential conceptual themes across the data—and these were the repeated patterns of the data at a more conceptual level than merely descriptive nodes. The reading was focussed more on already created nodes and the similarities and differences across nodes. A range of additional child nodes was created within parent nodes. Parent nodes were revised, thus helping to conceptualise potential themes and sub-themes. I engaged in reading through the nodes, formulating a series of mental maps and listing the potential themes. At this stage, a transition was noted in analysis, from descriptive nodes to more conceptual themes and sub-themes. Some examples of the initial thematic exercise (Figure 3.3 and 3.4) are provided. The middle boxes in the figures are emerging themes. The circles represent the commonly existing codes about acceptance (Figure 3.3) and belief about *Dewata* (God) influencing sickness as well as perinatal deaths (Figure 3.4).

Figure 3.4 Initial thematic exercise, acceptance of perinatal deaths

Source: Drawn by the author during thematic analysis technique

Figure 3.3 Initial thematic exercise, God *(Dewata)* in sickness and death

Source: Drawn by the author during thematic analysis technique
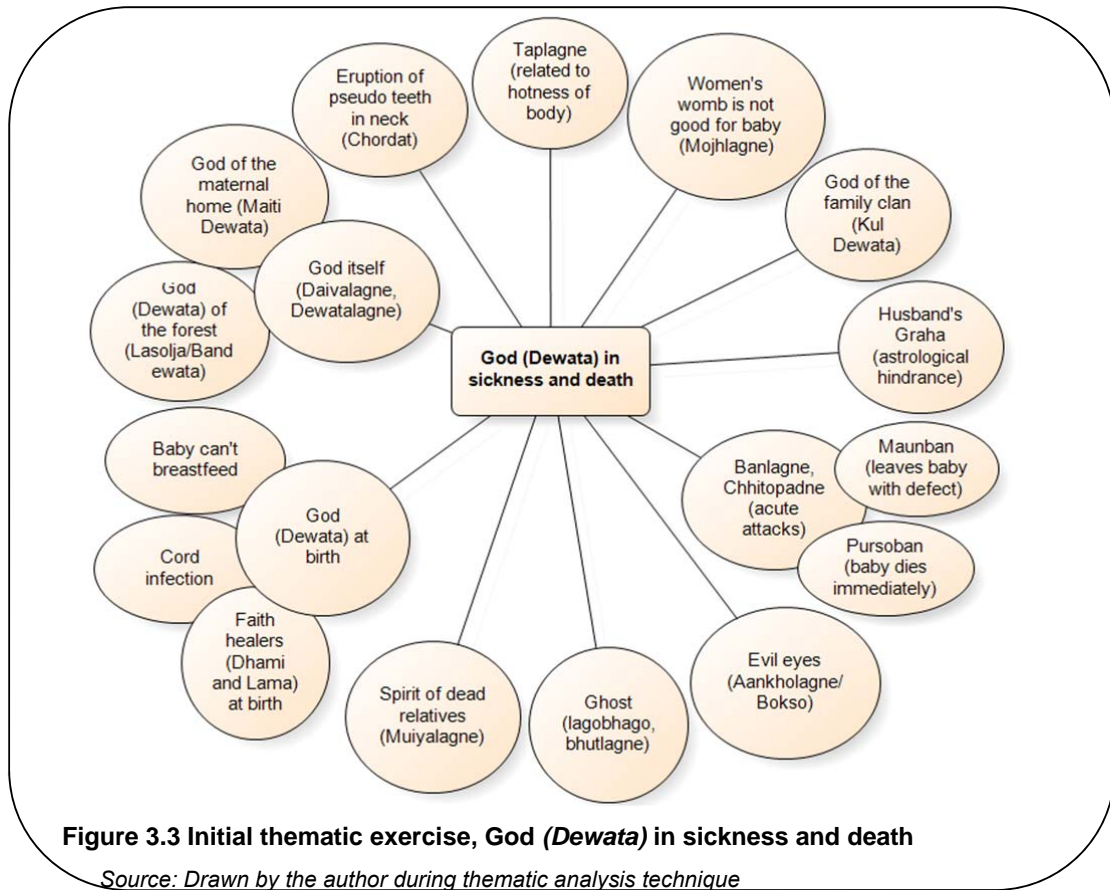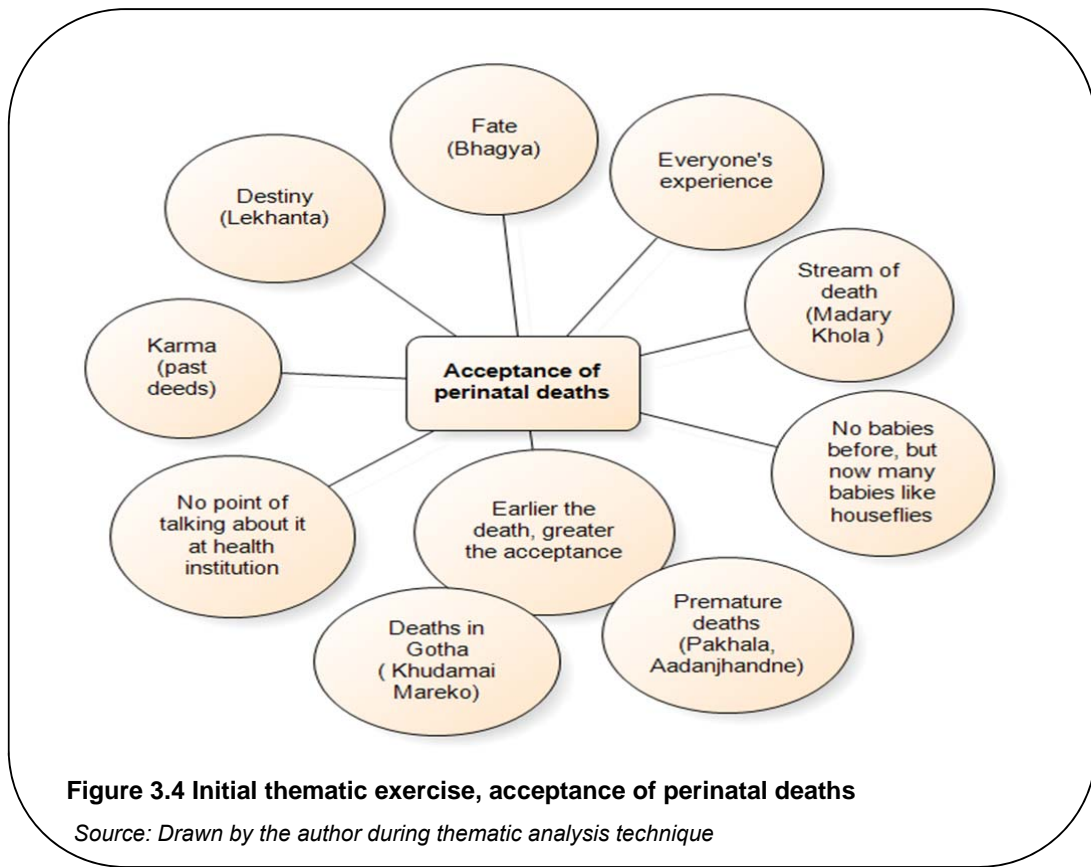
Likewise, Figure 3.5 presents an initial thematic mental map with descriptive themes on the bottom layer, more conceptual themes in the second layer and the main theme at the uppermost layer.

Figure 3.5 Initial thematic map in three layers more descriptive to conceptual themes (bottom to top)

Source: Drawn by the author during thematic analysis technique
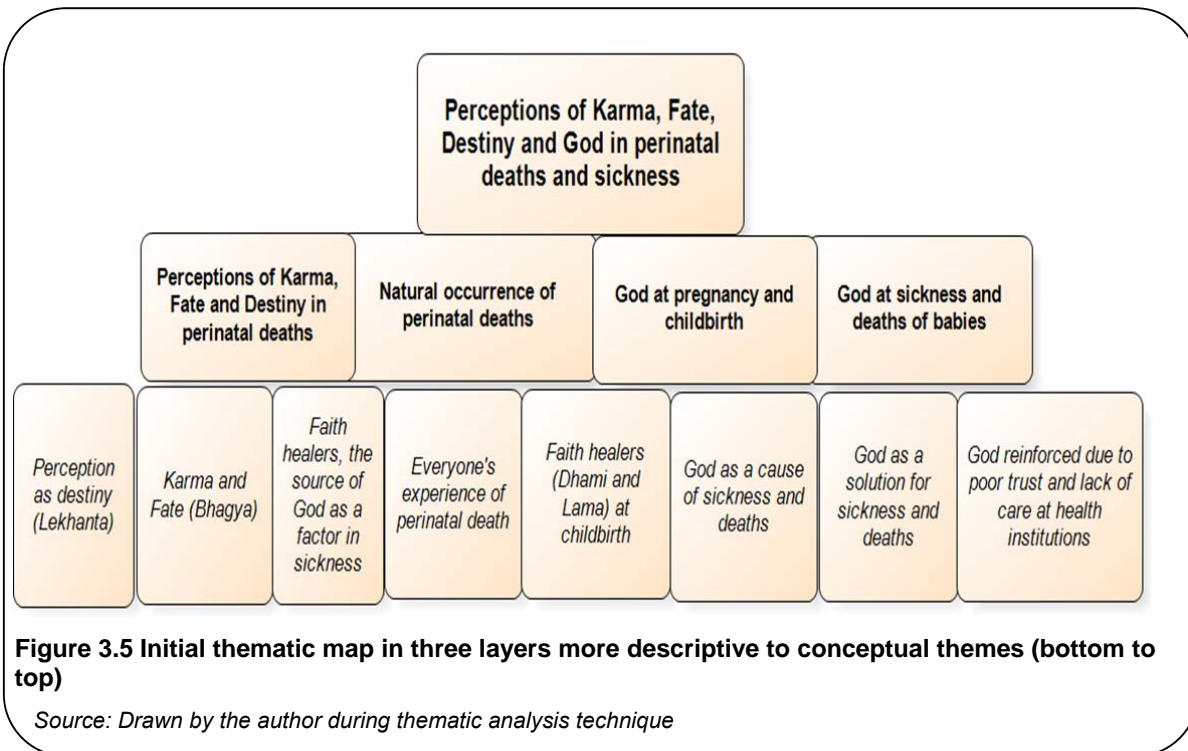
During this process, the notes taken during the field, the notes of each of the cases during transcribing and coding process, concurrent thoughts (the memos created in NVivo) and repeated reading through nodes and sub-nodes built in NVivo helped to produce mental maps and thematic exercises. The mental maps were drawn in 'Model' function of NVivo, which provided a flexibility to constantly revise previously saved mental maps and thematic exercises.

Phase 4, reviewing the themes

Phase 4 suggests refinement of already produced themes. Braun and Clarke (2006) emphasise reviewing at two levels: review of collated extracts under each theme to examine whether they form a coherent pattern, and a review of themes against the entire data set to see whether the meanings generated from each theme adequately represented the entire data set.

First, all relevant nodes were collated under the sub-themes (descriptive) and the conceptual themes (second layer) and the key theme (the top layer) as illustrated in Figure 3.5 in Phase 3. Data extracted under these various themes were read repeatedly. The reading process was undertaken using hard copies of transcripts as well as computer software. This made reading and examining coherence of data extracts under a particular theme easier and an effective exercise. To ensure coherence and consistency, I went through this process step by step starting with one

leading theme and its sub-themes. This process frequently took me back and forth to the original data set. Figure 3.6 illustrates the revised thematic map after reviewing the themes presented in earlier phases.

Figure 3.6 Satisfactory thematic map

Source: Drawn by the author during thematic analysis technique
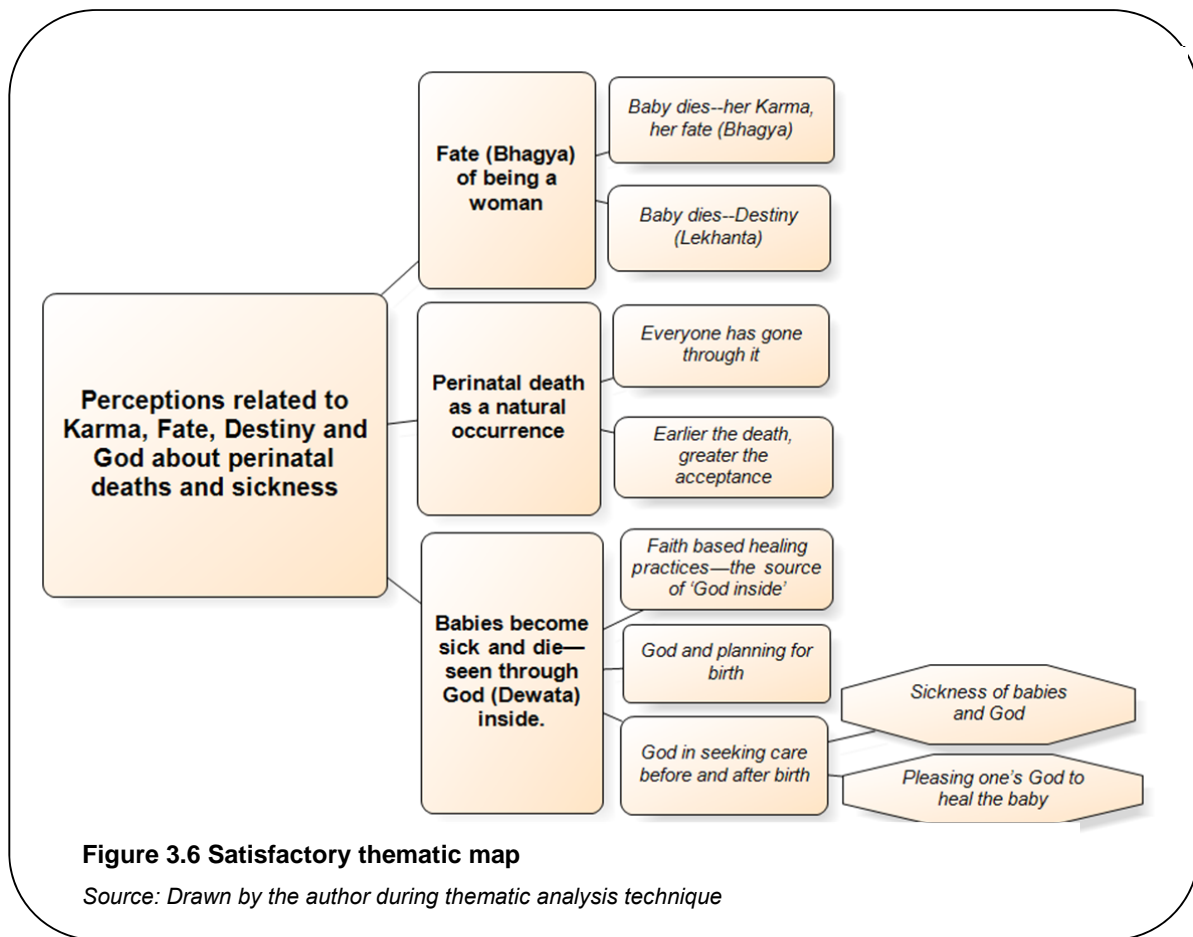
Figure 3.6 describes themes and sub-themes in the boxes. It was possible to move to the next phase once the thematic mental map of each leading theme was finalised. A similar process was continued until all other themes were reviewed in the study. During this phase, it became clear that collating extracts under a potential theme became more vivid, especially for checking the coherence and analytical claims of the themes.

Mental maps helped to examine meaning ascribed to each theme against the entire data set. The mental maps produced during the previous phase were revised. This led through a reflection and examination of relationships across codes, sub-themes and themes. The process of reviewing and reflecting on themes was helpful to ensure unit homogeneity and unit heterogeneity to check the internal and external homogeneity (Patton, 2015). Internal homogeneity is about the coherence in the pattern of collated extracts under each theme, and external homogeneity is about the distinction of a theme from other themes. Visual exercises were useful for searching higher level concepts and relationships among the themes. Mental maps worked like a constant input to

continue mental cognition. During this process, I was also continuously reminded of his epistemological commitments (Section 3.1).

Phase 5: defining and naming the themes

Braun and Clarke (2006) discuss defining and refining themes developed in phase 5. This involves identifying an essence of each theme and aspects of data that each theme captures. I reviewed collated extracts of each theme revised in the previous phase, and noted key messages from each theme, which was then gradually expanded with relevant quotes from the extracted data. During this phase, I frequently checked the source data to confirm the meaning of each quote within the context of each participant's story. Some themes with similar meanings were merged during this phase, and some new sub-themes were created. This practice facilitated the revealing of the relationships across various themes.

Phase 6: producing the report

In the sixth phase, Braun and Clarke (2006) suggest an examination of whether the themes are clearly evident from the data extracts. They recommend having enough data extracts, and to present the extracts that capture the essence of the point a researcher demonstrates. Having felt the importance of this, the thesis format was reviewed several times. Focus was given to providing a layout to the chapters and sections, and in providing signposts to readers in each chapter. During the writing and revisions of the result, it was realised that a table with all themes and sub-themes in the left column, and the underlying assumptions and possible implications in the right column for each theme, provided an early start to proceed to the discussion of the findings. This charting greatly helped to make notes about arguments and discussion of the study findings more systematically for each theme.

3.7 Ethical Considerations in the Study

Miller, Birch, Mauthner, and Jessop (2012) discuss different models of ethical applications: the universalist deontological, utilitarian/consequentialist and the contingent/situational models. According to the deontological model, emphasis is given on actions of a researcher to be guided by universal ethical principles such as honesty, justice and respect. The utilitarian/consequentialist model views an action ethical if its consequences are morally acceptable. More than the intent of an action, the rightness or wrongness of any action is judged based on goodness of an outcome. Likewise, from the perspective of a virtue based ethical model, a researcher's moral values, reflective skills, intuition and feelings are considered more crucial. This perspective considers a researcher's ethical position as situated and contextualised.

In this thesis, rather than viewing these different models as separate and leaning on one in particular, I gained insights and awareness about ethics in doing research thus preparing him to

more effectively view ethics as a continuous awareness of ethical principles throughout the research process, the intention of the research actions, and the relationships with the participants.

Ethical approval

This study went through the ethics approval process and followed the universal standards of research ethics as recommended by the Australian National Health and Medical Research Council (NHMRC) (NHMRC, 2015). Approval was sought and granted from the following places:

- Flinders University, Social and Behavioural Research Ethics Committee (Appendix 5.1);
- Nepal Health Research Council (NHRC (Appendix 5.2); and
- Study district: District Health Office, Mugu in Nepal that allowed access to mortality data and related documents, and allowed entry to the villages for this study (Appendix 5.3).

Orb, Eisenhauer, and Wynaden (2001) discuss ethical difficulties experienced in qualitative research such as those related to the study design, researcher participant relationships and interpretation of the data. Miller et al. (2012) and Orb et al. (2001) argue that rules as set in ethical guidelines alone may not be enough due to the fluidity of qualitative research design. A researcher may face practical considerations in a field situation such as in accessing participants. As a solution, Miller and colleagues suggest a situational and context based ethical approach to address practical issues. A researcher is required to continuously think ethically throughout the research process in qualitative research. Miller et al. (2012) put forward a reflexive model of ethics in the research process where a researcher moves further from reasoning and rationality, and acknowledges the emotions and feelings. Thus, it makes ethics a part of the relationship, shared values and interactions. Despite the inherent ethical tensions in qualitative study, Orb and colleagues discuss a researcher's awareness of key ethical principles of autonomy, beneficence and justice which could help to alleviate any ethical problems inherent in qualitative research.

Autonomy is about respecting the rights of individual participants, which is the right to be informed and freely decide, and the right to withdraw at any time during the study. The principle of beneficence is understood as doing good to others and preventing harm. Similarly, principles of justice could be implemented by listening to the voices of the minority and disadvantaged, recognising the contribution of the participants in the study, and being careful about practical considerations such as to not further burden the already vulnerable participants. Interviewing women with experience of perinatal loss has been frequently indicated as a sensitive research area (Liamputtong, 2007; Patel et al., 2007). In this research, a sense of appreciation was noticeable among women because for many of them it was the first opportunity to be heard. Just for courtesy, I had to talk to other women who wished to share their experiences even though they did not meet the selection criteria, although the conversations were not considered as research data.

Informed consent

All participants were briefed about the nature and purpose of the study, the likely benefits and risks of participating in the study and the right to refuse participation anytime during the study process. Participants were informed that the knowledge from this study could be utilised to contribute to the larger community and health systems to prevent the recurrence of similar problems in new mothers and families in the study communities and other similar communities of Nepal and other developing countries. Awareness of the interview as a moral endeavour (Kvale & Brinkmann, 2009) made the researcher more responsible and respectful of the confidential information which participants shared out of trust during the conversations.

Voluntary and informed consent was sought from all informants included in the study. Those who could not read and write, were requested to provide their thumbprint on the consent form as this was a recommendation from Nepal's NHRC. Participants agreed to participate in the study based on gatekeepers' verbal information. As a final consensus, the consent form was read by myself. The study utilised 'a letter of introduction' (Appendix 1) and 'an informed written consent form' for participants (Appendix 2) to ensure informed and voluntary participation.

Privacy and confidentiality

Participants in this study were assured of privacy and confidentiality of their personal identification. Data were kept confidential, stored on my computer only and protected by the Flinders University server. The informants were kept anonymous by using pseudo names in transcriptions and in this thesis. Photos reflecting the remoteness and context of the study site and health facilities were taken with permission.

Harm management

During each interview, I remained aware of potential psychological harm to women and their family members as a result of recalling sad memories related to their babies' deaths. To minimise the harm, women were reminded of their ability to stop the interview at any time when they felt it too difficult to share their stories. During the interview, they were listened to with due respect as Liamputtong (2007) suggest that this could help relieve any sadness and possible psychological harm of interviewing participants about sensitive topics such as involving deaths of infants and stillbirths. Due to the evolving nature of qualitative study (Van Olmen et al., 2012), it might be difficult to assess the risk at the outset. A researcher is advised to stop and re-schedule or cancel data collection if participants appear anxious during the interview process. The majority of interviews went smoothly with no signs of participants' distress. Sharing my experience of perinatal loss in my own family and kinship, and the post-interview informal conversations became rather soothing, more like catharsis to the study participants. However, I myself had some upsetting moments while listening through the sad stories of women and families during interviews and also

during transcribing them. In this regard, I reflect that my meditation (mindfulness) practice became of immense help throughout the fieldwork and transcription.

Of the total of 42 interviews, three interviewees—two nurses and a young girl, became emotional during their interviews. While recollecting the memories of women losing babies in health institutions, the two nurses broke into tears. After this, we agreed to continue our conversation the next day. In addition to these nurses, it was observed that one young girl (Laldevi[6]) felt guilty that she gave birth at quite a young age without being physically and psychologically prepared for birth, stopped schooling, and lost her newborn boy. Now, she would like to postpone pregnancy at least until she has completed her schooling. I ensured that she was not further distressed. He followed her up with her natal and maternal family to assure them about not to pressurise her for immediate pregnancy. I was not a qualified psychological counsellor, and none of the participants was required to arrange any specialist psychological counselling.

My previous experiences on mindfulness/meditation became more helpful, allowing participants to share their story, and listening with care and concern. It was also realised that sharing of perinatal death experiences of my own family members (my own sibling, and one of my nephews), and that of my work settings before as a community level health trainer, put women and their families at ease. It facilitated the participants to openly share their experiences. As earlier described, a number of women with elder infant deaths, toddler and under-five deaths wished to be interviewed to share their stories. Out of courtesy in the villages, I had to informally chat with them and listen to their stories and concerns surrounding their experience of care seeking from health institutions and hospital.

Ethical consideration within the cultural context

The interviews were planned at a time convenient to the participants in order to accommodate daily work, mealtimes, baby care etc. I freely allowed any family members to join in the interview if they were at the interview site and which was culturally appropriate and also added family members' views about perinatal deaths. Interviews were similar to those outlined in Riessman (2008) in the interview context of Indian village women where it is natural for their family members to watch, listen and put their views during the interview. When I was interviewing women, it was not possible to maintain their individual privacy. There were many occasions when family members came in during the interviews, added their views and left at will.

Contrary to my observation in Australia and other western countries, it was seen that asking personal questions in relation to themselves, their family and their lives made them feel valued and

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[6] Pseudo names have been used for all participants in this study. The names given in this thesis are not the real names of the participants. All of the original names have been changed for the sake of confidentiality and anonymity.

respected which is due to the cultural context in the Nepalese villages. It was frequently commented that hardly anyone before was interested to listen to them and their stories of child deaths. Other researchers (Liamputtong, 2007; Moore & Miller, 1999) note that the needs and concerns of vulnerable people are often not considered in scientific literature. It is considered that research with vulnerable groups and communities is often difficult to carry out, is assumed ethically problematic and often faced access problems for researchers.

Poor perinatal survival is the most pressing public health problem in many developing countries including in Nepal, and people in remote and rural areas often undergo unfair advantage of research and policy attention. To address the most pressing social issues, it demands research with vulnerable participants such as in this study. Researchers have argued that avoiding research with such groups of people considering them sensitive, is an avoidance of responsibility (Liamputtong, 2007, p. 20; Sieber & Stanley, 1988). It is believed that this research has done these people a justice by listening to the voices of the women who lost their babies in the remote and disadvantaged mountain villages of Nepal. Likewise, as already stated, my flexible approach of allowing family members to add their comments while interviewing the women at home, has been a culturally fair approach. Otherwise, it was realised that some family members could have put their women in an uncomfortable situation regarding why they wanted private interviews.

3.8 Limitations

I acknowledge a number of limitations to data collection and analysis. They included:

Language barriers in data translation

Retaining meanings while translating interviews from native language into English was a challenge. However, I maintained the quality of translation by auditing six random transcripts through five bilingual (Nepali and English) experts (three current and two past PhD Students from Flinders University) as described in the transcribing section.

Member check

Member checking is a participant validation technique to ensure accuracy of description and interpretation of data (Birt, Scott, Cavers, Campbell, & Walter, 2016; Brewer, 2000). It was impossible to member check by contacting participants after the translation and transcribing of interviews. Remoteness of the villages under study and poor infrastructure including electricity supply limited on-time transcription and translation of data. Digital recorders were charged using portable batteries. In order to initiate analysis after each interview, I listened to the audio files and took notes on emerging issues and any improvement in the subsequent interviews. Moreover, as most of the women and family members were barely literate, checking through written interview texts or analysed data was practically inappropriate other than clarifying the meanings and their responses during interview and post-interview chats while I was in the field.

Nepal's 2015 major earthquake during the fieldtrip made it further challenging to travel between the villages and re-visit participants. I had to rely on the clarifications about the meaning of key local terms and participants' stories which were verified while in the field immediately after interviews, after documenting the interview notes and the repeated listening to audio records as felt necessary. The fieldwork context was also different—everyone was concerned only with the earthquake. This made me leave the field earlier than expected.

3.9 Conclusion

Overall, this chapter has described the qualitative methodological approach, methodological principles underpinning this study, and method of data collection, describing also the rationale behind choosing them. The qualitative interviews were the primary source of data supplemented by the review of policy documents, field notes of observation in the field settings, and the informal chats. A total of 42 interviews were conducted with women and their family members, which were supplemented by 11 interviews with service providers, and remaining nine interviews with female community health volunteers, local stakeholders, support staff at health facilities and a traditional healer. The study went through the ethics approval from the Social and Behavioural Research Ethics Committee of Flinders University, and from the ethics board of the Nepal Health Research Council. In the following chapters, I will describe the study findings beginning with study field contexts, the detailed contexts of the study sites, the socio-economic situations and the local health system. The information collected in this study is valuable for shedding light on the hidden mysteries of perinatal mortality in the remote mountains of Nepal, which will be unravelled in the subsequent chapters.

CHAPTER FOUR

STUDY FIELD CONTEXTS

In the previous chapter, the qualitative nature of the methodological approach adopted in this study was discussed, followed by the key methodological principles: participants as the authentic sources of knowledge, the researcher's reflexivity in the study, and experiences about perinatal deaths through natural interactions with women and families in the field setting. The objective of this chapter is to provide a detailed context of the study site including its socio-economic characteristics and local health system. In qualitative studies, in particular, a detailed description of the broader socio-economic conditions of the study site makes it easier to understand and interpret data collected from local experiences and observations (Schensul & LeCompte, 2013). This chapter presents a description of the field area, its location and geography, the people, the living conditions of villagers, and the organisation of health care at district and village levels. The description provided in this chapter is expected to help the readers grasp the general situation in which women live and give birth to babies who often do not survive the perinatal period. Such information is vital for a good understanding and interpretation of the findings.

4.1 Field Area, the People and Fieldwork

4.1.1 The Field Area, Location and Geography

This study was conducted in a remote rural mountainous district, *Mugu* as shown in Figure 4.1. Mugu is located in Nepal's most disadvantaged region, the *Karnali* zone of the mid-western part of the country. Districts in Karnali have the worst child survival situation, recording one of the highest neonatal, infant and under-five deaths in the country (MOHP et al., 2012). Of the five districts in the Karnali, Mugu is considered the most disadvantaged district in the region.
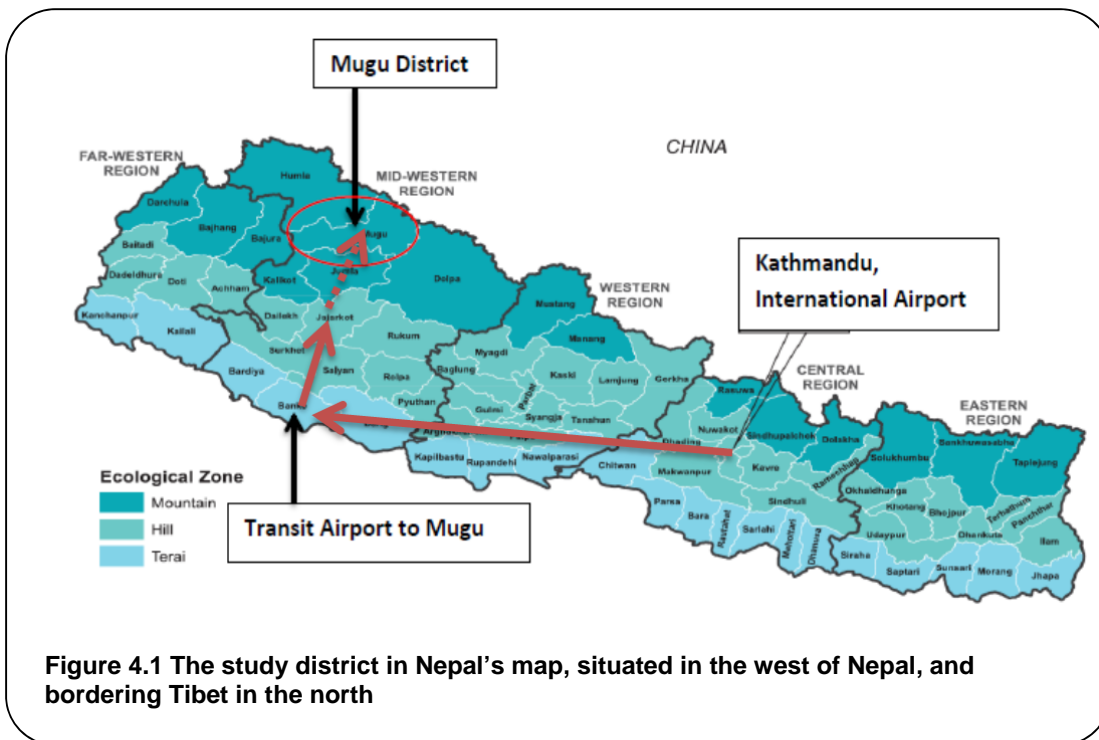
Figure 4.1 The study district in Nepal's map, situated in the west of Nepal, and bordering Tibet in the north

More than 90% of the total land area of Mugu is situated in the mountain ranges above 2,000 metres and half of the district is situated above 4,000 metres in the high Himalayan ranges (DHO, 2012). Mugu consists of 24 villages (Village Development Committees), and is famous for its beautiful lake called Rara (Plate 4.1).
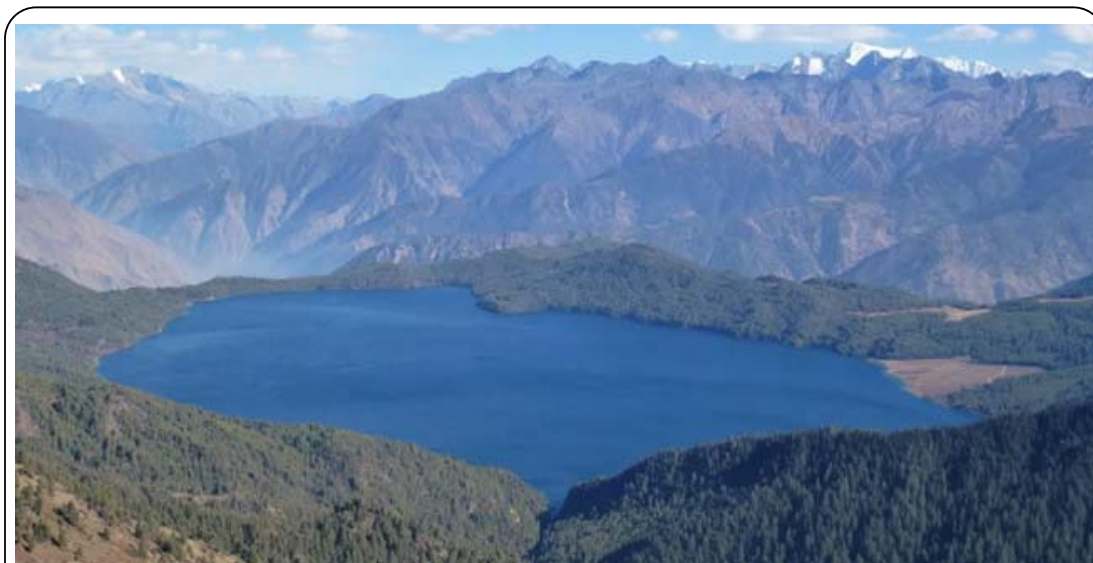
Plate 4.1 The Rara lake of Mugu

Photo Credit: Author

Mugu ranks as one of the lowest districts in the country in terms of the Human Development Index (0.304) (National Planning Commission [NPC] & United Nations Development Programme [UNDP],

2014). At an international scale, the HDI value of 0.304 is lower than that of countries with the lowest HDI in 2013, namely Ethiopia (Africa) and the Central African Republic (IRIN, 2013).

Mugu has a population of about 60,000 (DoHS, 2014). Only half of the district population is literate, with a much higher literacy for males (60%) than that for females (38%) (DHO, 2014). The district has 144 schools, including primary and secondary schools, and one undergraduate college.

The district has no reliable and quick access to transport. In good weather conditions and if the domestic airport is operational, Mugu can be reached in a day from Kathmandu. However, in most cases a flight connection from a western city, Nepalgunj to Mugu district airport is not possible or may be delayed for up to a week. Though the district has been recently connected to the Karnali highway, this road only functions during summer when weather is good and the road is not affected by snow and landslides. One cannot trust the road, nor the flights to travel to Mugu. Therefore, most of the time, people have to walk to reach the district.

The district airport is located around three hours walking distance from the district hospital (Figure 4.1). Even if the flights are regular, stretchers are the only options to bring sick people up to the airport, which might take another two to four hours.

4.1.2 The People

The district consists of two major ethnic groups: *Khas/an* and *Lama*. Khas are from the *Aryan* race and have been the local inhabitants for hundreds of years in the hill and mountain regions. The *Lama*s are of Tibetan descent who have made the mountains their home. They belong to the *Mongolian* race. Some *Lamas* prefer to be called a *Karmarong* instead of a Tibetan descendant which means they are the true owners of the mountains from ancient times. The *Lama*s constitute almost 9% of the total population of Mugu (UNICEF Nepal & Health Education, Research and Development [HERD], 2014). They follow Buddhism and speak their own local language called *Bhotebhasa*. The *Khas* community has several caste groups including upper and lower castes. The upper and lower caste strata are also evident among the *Lama*, but not as prominently as in the *Khas* community. The *Khas* people follow Hindu religious beliefs and speak the national Nepali language, but their local dialect is different. Although they appear to be two different groups of people, the *Khas* and the *Lama* in the district have intermingled in terms of their shared beliefs and practices for many years.

4.1.3 Livelihood and Life in Mugu

Nationally, a quarter of the population of Nepal lives below the poverty line. However, the percentage of people living below the poverty line is much higher in the mountains of the Karnali region (42%) than in the plains and the hilly region of the country (Central Bureau of Statistics [CBS], 2011; Integrated Regional Information Networks [IRIN], 2013). Among the Karnali districts, Mugu is considered the most disadvantaged district with poor health (Table 4.2) and social

indicators, such as low literacy, low life expectancy (only 49 years) (DHO, 2012), and only half of the households with access to water within 30 minutes' walk (Table 4.2).

Table 4.1 Key health and social indicators in Mugu

Indicators	National Status	District Status
Human Development Index (HDI)[a]	0.548	0.304
Adult literacy rate (%)[a]	59.7	49
Life expectancy at birth, average of both sexes (years) [a]	69.6	56
Proportion of people living below the poverty line (< 2 dollar a day) [a]	25	46
Total Fertility Rate (per woman) [b]	2.1	>3.4
Households with access to water within 30 minutes (%)	85 [d]	51.7 [c]
Proportion of women with antenatal contact (fourth visit) [a]	50.57	29.6
Proportion of women attending birth with Skilled Birth Attendants [a]	43.45	21.4
Postnatal contact (first) [a]	59.23	44
Complicated cases received by Basic Emergency Obstetric and Newborn Care (BEONC) sites (hospital and PHCC) (%)	23[g]	21.0 [c]
Women with complications successfully managed by BEONC sites (%)[c]	23 [g]	19.1 [c]
Complicated cases timely referred to the Comprehensive Emergency Obstetric and Newborn Care sites (%)	NA	2.1 [c]
Children breastfed within one hour of birth (%)	48.7 [e]	45.4 [c]
Children <6 months exclusively breastfed and initiated breastfeeding within 1 hour (%)	57[f]	22.3 [c]
Mothers washing hands before feeding child (%)[c]	NA	1.0
Incidence of diarrhoea (per 1,000 under-five children) [c]	629 [g]	794.0
Incidence of Acute Respiratory Infection (per 1,000 under-five children) [c]	244 [g]	429.0

Source: [a]District Health Office, 2011; [b]MoHP et al, 2012 ; [c]UNICEF Nepal and Health Research and Social Development Forum (HERD), 2014[3] ; [d]WHO (2015c); [e]UNICEF (2016); [f]World Bank (2014); [g] DoHS, 2014; NA: Not Available

Three quarters of the district poplulation relies on agriculture for its subsistence, but only 5% of the district land is cultivable, most of which remains unirrigated (UNICEF Nepal & HERD, 2014). Barley, potatoes, oats and millet are the most commonly produced staples in Mugu district. Paddy rice is also common but not grown as much as other foods. The land in Mugu lies on a slope, and the crop fields are terraced in small sizes (Plate 4.2). Villagers move up the plateau in search of cultivable flat land for cropping, and grazing cattle and sheep. It seems this is why they started making *Lekhghar*, the little mud and stone houses, to stay in during seasonal cropping.

Plate 4.2 A village woman and a child working in a millet field in the second village

Photo Credit: Author

Mugu is one of the most food insecure districts in Nepal. According to the World Food Programme assessment (IRIN, 2013), other than Mugu's neighbouring district, Jumla, all remaining districts in Karnali region including Mugu, produce food that is merely sufficient for three to six months a year. Karnali is the poorest and the most food insecure region of Nepal. With about one-third of the population living in food insecure conditions, the government has provided subsidised rice to Karnali districts including Mugu (Plate 4.3).

Plate 4.4 Villagers waiting having received the sacks of rice from the District Food Corporate Limited, Mugu

Photo Credit: Author

Villagers from the *Lama* community go to the nearest Tibetan border once or twice a year to purchase common items of food such as rice, sugar, oil and tea, and clothes and pots. It takes them more than two days' walk to reach the market. Mules and yaks (Plate 4.4) are the most common means of transportation of goods in these villages.

Plate 4.3 Men bringing grocery items on their yaks in the villages

Photo Credit: Author

4.1.4 Gender Status and Roles

In 2014, according to the gender inequality index (GII), Nepal ranked 108th out of 188 countries with a GII score of 0.489 (UNDP, 2015). Poverty and gender inequality indexes in the rural areas of Nepal, particularly in the mid and far-western regions including mountainous areas of Karnali region are more pronounced compared to other parts of the country (NPC & UNDP, 2014). The situation of women is much worse in the Karnali region than in other parts of the country. Women suffer from poverty and unfavourable gender roles. Women do not have their own formal names and are known by their husbands', sons' or fathers-in-law's names (such as someone's wife, someone's mother or someone's daughter-in-law). In daily life, women are fully occupied with laborious work including cooking and feeding family members; planting and harvesting crops; collecting grass and firewood from the forest (Plate 4.5); and fetching water from the tap/well.

Plate 4.5 Women from the first village returning home after a day collecting firewood from a forest in the national conservation area

Photo Credit: Author

Pregnancy and childbirth are not considered as special events by the people of the villages, with no special attention paid to pregnant women in terms of care and nutrition. Whether pregnant or not, taking nutritious food such as fish, meat, eggs and vegetables is not considered important for women. I frequently saw village women selling eggs and green vegetables in the markets at the district headquarters, but they used the proceeds of the sale to buy clothes or rice from the market. Cultural beliefs such as isolating women during menstruation and the postnatal period are common in the villages. Smoking *Sulpa*[7] is common among both men and women and is the only moment of rest in many a woman's life.

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[7] Sulpa is a pipe made of clay for smoking *Tambakhu*—a locally produced tobacco.

Men principally work as shepherds although some travel to the nearby cities in India for work. Binge drinking is a common practice amongst men particularly among *Lamas*. The consumption of *Chhyang*, a local alcoholic beverage (Plate 4.6), produced from fermented millet or rice is common even among pregnant women.

Plate 4.6 A local woman producing the alcoholic beverage, *Chhyang*

Photo Credit: Author

4.1.5   Fieldwork

Time restrictions for fieldtrip

The study fieldwork was conducted between mid-February and mid-June 2015 which is the most appropriate time to visit the villages. There were some restrictions that had to be taken into consideration in selecting the best time for the fieldtrip. These include:

During hot season (between April and June), villagers usually move to settlements up in the mountain (Table 4.1) called *Lekhghar*, which are small mud and stone huts and located close to farmland. Family members are separated during seasonal cropping and harvesting time. Young men and young women including son and daughter-in-law stay at *Lekhghar*. Houses in the usual settlement areas, which are generally situated in low lying areas, are called *Aulghar*. These *Aulghars* are made of stone, but slightly larger than their houses in *Lekha*. During this time, the older members of the family (mothers-in-law, fathers-in-law) and younger children stay in houses located in low lying areas, to take care of the house and graze their cattle in the bushes nearby.

In addition, the villagers leave their villages usually after June when snow starts melting to collect *Yarsagumba* in the high altitude snowy mountains. *Yarsagumba (Ophiocordyceps sinensis)*, also called caterpillar fungus, is used for treatment of fatigue, gout, and cancer in Chino-Tibetan

medicine (Shrestha, Shrestha, Ghimire, Nepali, & Shrestha, 2014). It is also used as a tonic to gain vitality. Harvesting the fungus is a livelihood and one of the major sources of income for the people in mountain districts of Nepal, such as Mugu. The absence of local residents and closure of most health institutions during this period made the data collection impossible therefore which the period after June was deliberately avoided.

The period between November and January is also not a good time for fieldwork as most villagers migrate during this period (Table 4.1) to the low lying areas, district headquarters, to neighbouring districts, and to Nepal's capital city Kathmandu, in order to avoid snow fall.

Table 4.2 The villagers' temporary moves between the villages

Months	Climate	Location	House	Occupants
April-mid July	Hot weather	Up in the mountains	*Lekhghar*	Usually the son and daughter-in-law
Mid July-February	Cold weather	Low lying areas	*Aulghar*	All family members
November-March	Snow fall	Migration to low lying areas	*Aulghar*, temporary move to other places	All family members

Source: Fieldwork, 2015

Transport to the study areas

The weather was cold when the field trip commenced in February 2015. A domestic flight was used from a western city of Nepal, Nepalgunj (Figure 4.1, the transit airport) to Jumla, a district neighbouring Mugu. Due to weather changes and snowfall, flights to the study district were closed for three months and did not resume for the entire fieldwork period of five months. It required two days walking to reach Mugu, the study district from the neighbouring district. A support staff member of the DHO from the neighbouring district accompanied and guided me during the field trip. On the way to the study district, we had to trek along a snow capped road with very low visibility as shown in Plate 4.7. This resulted in many occasions of slipping and potential falling; however, it turned out to be a wonderful adventure with my guide who was an experienced marathon runner and a mountain climber.

Plate 4.7 The researcher trekking to the fieldwork villages, February, 2015

Photo Credit: Author

4.2 Study Villages

Participants in this study were recruited from two villages (Figure 4.2). These villages[8] were purposely selected after consultation with the chief, public health nurse and child health supervisor of the DHO and review of available records. The selection of the villages was based on accessibility, population size, health care and the possibility of collecting rich information with village birthing sites in each village, and a nearby district hospital (in the first village). It also allowed the study to recruit mixed ethnic groups of *Lama* and *Khas* people to broaden the understanding of the contextual factors influencing poor perinatal survival in the villages.

Figure 4.2 Study villages in Mugu district

Source: District Health Office, Mugu

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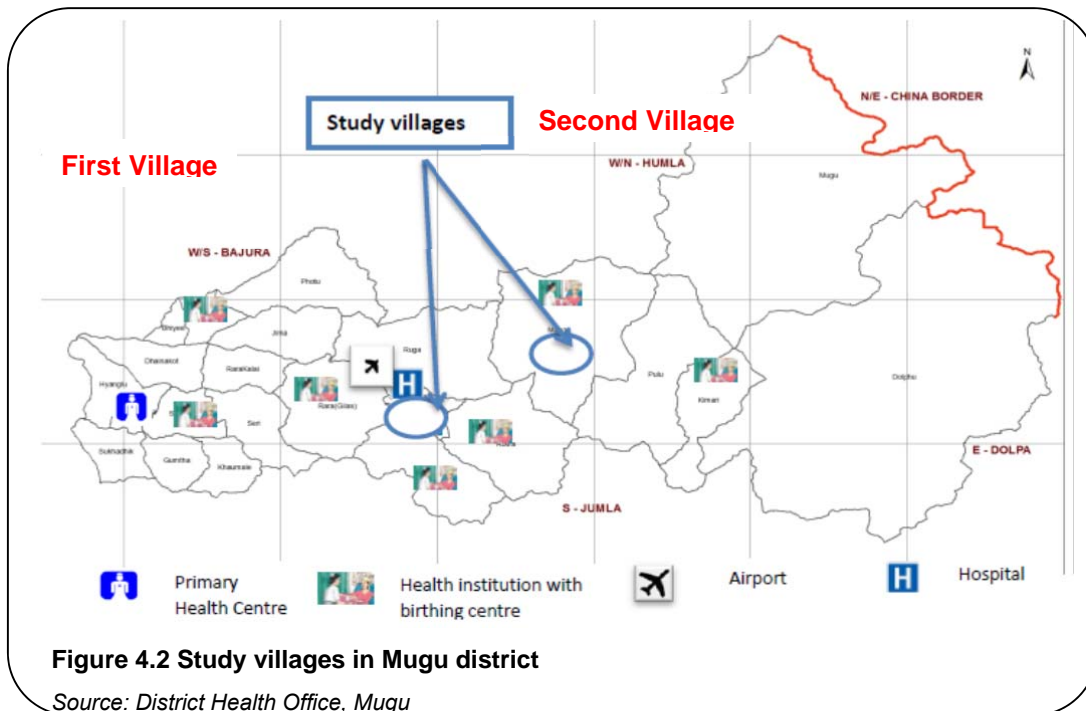
[8] The names of the villages have not been mentioned for ethical reasons.

The first village

The first village (Figure 4.2, Plate 4.8) is located in the west of the district. It is near the district headquarters providing villagers physically better and multiple accesses to health centres including the district hospital.
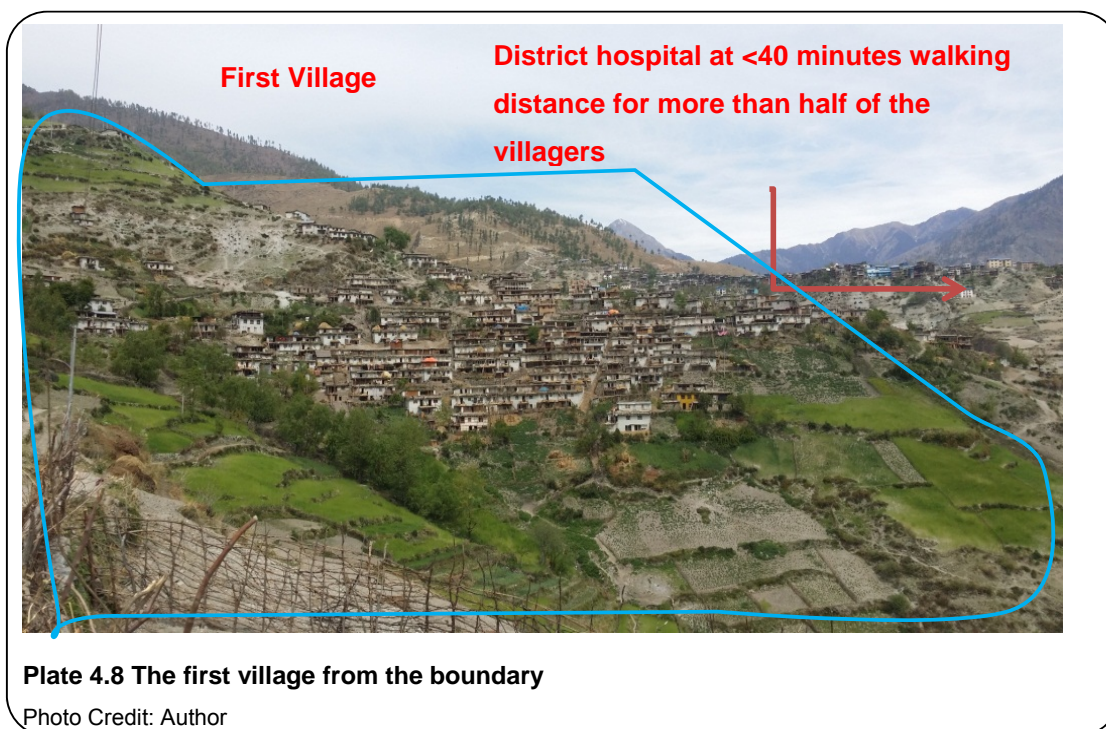
Plate 4.8 The first village from the boundary

Photo Credit: Author

Approximately 4,000 people live in this village. Of the total 24 villages, the local government office reports this as the model village in the district. This village has its own birthing centre, and a village health facility. It takes between 30 minutes to two hours' to walk to the district hospital. The village based health institution is staffed by a Health Assistant (HA), Auxiliary Health Worker (AHW), Auxiliary Nurse Midwife (ANM) and a support staff. The community birthing centre has an AHW, SBA and a support staff. Besides access to the district hospital, more than half of the villagers from this village have easy access to a health institution in the adjoining village (the district headquarters) within less than 30 minutes' walk. Other facilities include:

- Community birthing centre that has been run for more than three years with support from the local community and an NGO. This is situated in the middle of the village with easy access to all the villagers.
- Private pharmacy shops.
- One private clinic located in the district headquarters.
- One primary and one lower secondary school. It also has access to the secondary schools and college at district headquarters located within 30 minutes to two hours on foot.

This village has relatively good cultivable land, which has been the major supplier of vegetables to the district headquarters. The population is entirely made up of *Khas* people, both from lower as well as upper castes. Villagers live in densely crowded houses which are often adjoined (Plate 4.8). The houses are made of mud and stone, usually two-storey with only one bedroom. The first storey is the ground floor and the second storey is the first floor. People stay on the first floor, and keep their cattle on the ground floor. The only bedroom on the first floor is called *Buigal kotha* used by the older people of the family. The kitchen oven is usually in the middle of the floor and members of the family sleep in the kitchen around the stove. There is no water supply or toilet inside the houses. People have to fetch water from taps located at 10 to 15 minutes' walk. During their menstruation and postnatal confinement, women are not allowed to use the public taps/wells.

The village has many temples, and also *Thaan/Gadhi,* which is a symbolic representation of *Dewata* (God). The people make this *Thaan/Gadhi* inside their house, and one can find them anywhere in the village, in the middle of settlements, near the bushes as well as in farm areas.

Wheat, millet, rice, barley and potatoes are the most commonly produced food in the first village. Selling vegetables, sheep and chicken in the nearby district headquarters is the villagers' main source of earning cash. In addition, it is common for the men from this village to work as daily labourers (transporting goods and construction work) in the district headquarters and to go to India and nearby cities for work.

The second village

This second village (Figure 4.2, Plate 4.9) is located in the north-east of the district. It takes about a day's walk to get to the district headquarters from this village.

Approximately 3,000 people live in this village and there is a mixed community of *Khas* and *Lama* people. Villagers live in five different clusters, two large clusters of *Lama*s and three small clusters of *Khas* people. Villagers have access to only one village based health institution with a birthing unit staffed by three SBAs, two AHWs, one HA and a support staff. The health institution is located in the middle of the village. The village is scattered across several settlements. For some people, it takes as long as three hours' walk to reach the health institution. As reported at the district level, the health institution located in this village is one of the best functioning 24-hour birthing sites in the district.

Other facilities in the village include:

- Two small private medical shops
- Four primary schools and a higher secondary school.

Plate 4.9 A part of the second village

Photo Credit: Author

The main locally produced foods are potato, barley and millet. *Bhote Chiya*, the locally prepared tea by *Lama* people; *Chyyang*, the local alcoholic beverage; and *Thukpa* (meat, vegetable and noodle mixed soup) are common and popular among the *Lama* community. They purchase rice, tea, wheat and other daily necessities from the district headquarters as well as from the Tibetan border. They go to purchase these goods with their donkeys and yaks, two or three times a year.

There are many stupas in the village made in memory of dead persons of the *Lama* families. *Lama* people follow Buddhism. However, the traditional care and beliefs with *Dhami/Jhakri* (faith healers) are common, and similar to that of the *Khas* community. Both communities share similar beliefs about birth and baby care.

The above section described the field area including geographical location, people and their life and livelihood, fieldwork and the study villages. The next section describes the organisation of health systems and interventions related to maternal and neonatal health at district and village levels.

4.3 Health System Structure and Interventions

4.3.1 Organisation of Health Care at District and Village Levels

The national health care system in Nepal is organised through three departments under the Ministry of Health and Population:

- Department of Health Services (DoHS), as the key apex body to facilitate the implementation of health care services throughout the country and extended up to the communities (DoHS, 2014);
- Department of Drug Administration (DDA); and
- Department of Ayurveda (DOA).

Health care delivery structure extends from district level down to the communities (DoHS, 2014; Rai, Rai, Hirai, Abe, & Ohno, 2001). The district level health care delivery comprises DHO with public health sections and a district hospital. The DHO is the main government body to ensure health care throughout the district as a health wing of the District Development Committee (DDC), the local government. In Nepal's administrative structure, the DDC is the key administrative unit with its extended sub-units called Village Development Committees (VDCs) down to grass roots level. The VDC is further divided into wards, which are small settlement areas. At the village level, the extensions of DHO include peripheral health institutions, such as: Primary Health Care Centre (PHCC), Health Posts (HPs) and Sub Health Posts (SHPs). Their services are extended further to the communities and settlements through Female Community Health Volunteers (FCHVs), Mothers' Groups (MGs) and Outreach Clinics (ORCs), (Figure 4.3).

Plate 4.10 The District Health Office/Hospital, Mugu

Photo Credit: Author

Figure 4.3 Structure of health care delivery system at district and villages

Source: Drawn by the author; fieldwork, 2015
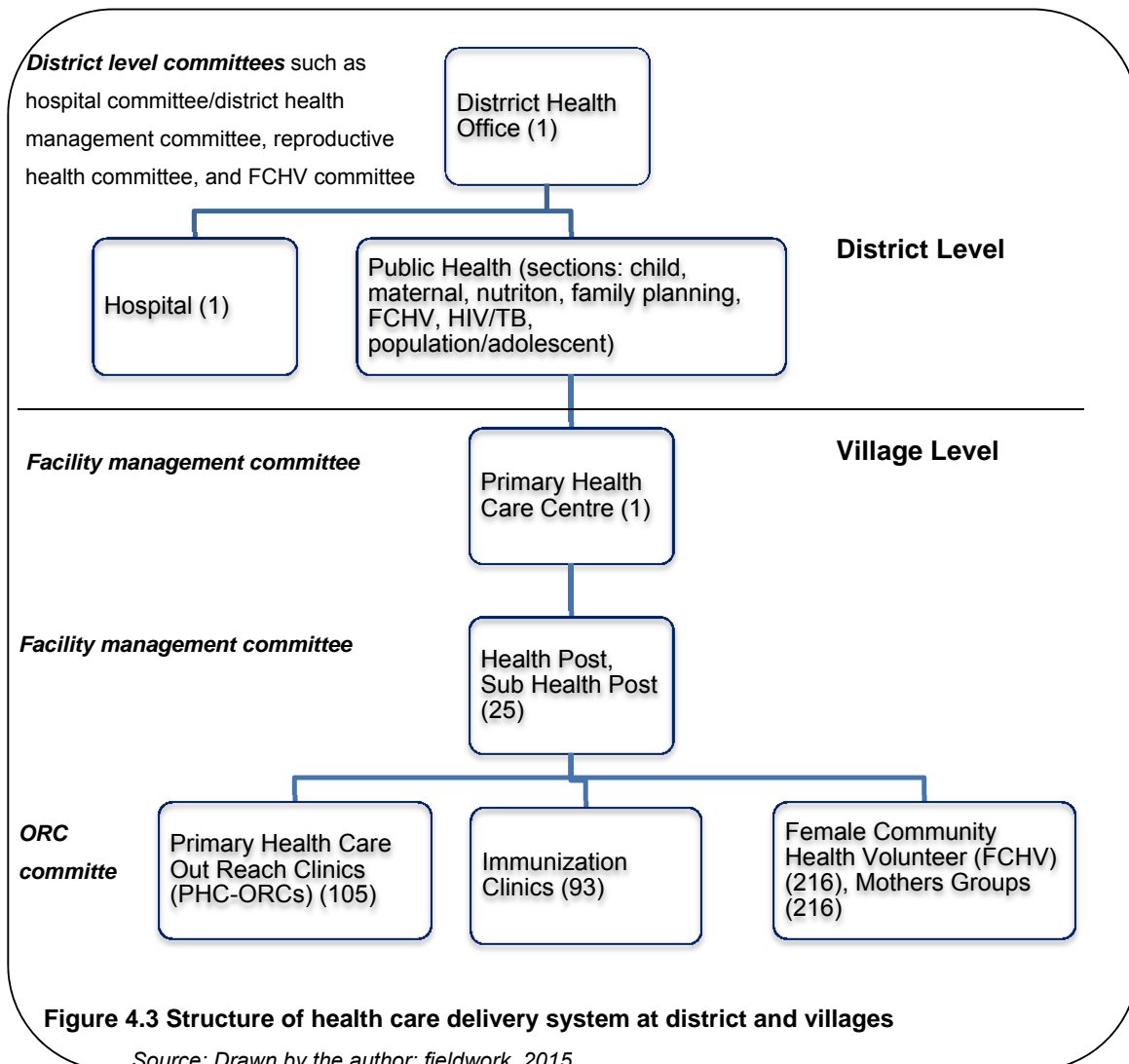
The study district has one district hospital (Plate 4.10), and 26 peripheral health institutions in the villages: one PHCC, 11 HPs, and 15 SHPs (DHO, 2012). Of the 26 health institutions, nine are reported as birthing centres, providing 24-hour birthing services. Linking these peripheral health institutions to communities are 105 ORCs based in sub-sections of villages, and 216 FCHVs—one at every ward and their corresponding Mothers' Groups (Figure 4.3).

Mugu hospital has 15 beds. The hospital has a lab/X-ray/Ultra Sonogram section, general out-patient section, maternal and child health section carrying out antenatal examinations, and general admission and a labour room. Hospital beds are not maintained properly with many patients forced to lie in makeshift beds outside on the hospital grounds (Plate 4.11).

Plate 4.11 Women waiting around, patient lying on the ground of hospital premises
Photo Credit: Author

The DHO has an approved position of a medical superintendent having a specialised qualification in medicine, two medical officers with a Bachelor of Medicine and Surgery degree, nurses and paramedics. However, the medical superintendent exists only on paper as it is already years since that district had a medical superintendent in the hospital. Frequent turn-over and absence of health workers is seen as a chronic problem in the district. I was fortunate to meet a medical officer during this fieldwork. This medical officer was also working as an acting chief of the DHO—thus overseeing both the management aspect of district level public health programmes, the village level health institutions as well as the district hospital. Although two additional medical officers were deployed in the district besides the approved regular positions, none of them was present during the fieldwork (February to June, 2015) in the district.

Whilst in the field, I also met a nurse and a gynaecologist from an international voluntary agency who were supporting the district hospital to enable them to resume Caesarean Sections (CS). However, due to lack of an anaesthetic assistant in their team, the district hospital could not resume provision of CS service by the end of this fieldwork.

Each institution has its own management committee consisting of health service providers and local community representatives (Figure 4.3). At the district level, this committee is called the District Health Management Committee (DHMC), represented by the local development officer, or the chief of the local government as the chairperson. This committee makes decisions on all affairs related to health care at the district level. Specifically, for activities related to reproductive health care. In addition, DHO has a Reproductive Health Coordination Committee (RHCC) comprising government as well as non-governmental agencies working in the fields of maternal health (including uterine prolapse), child health, HIV/AIDs and adolescent health. At the village level, the health facility is run by a committee called Health Facility Management and Operations Committee

(HFOMC) which represents health workers from village health institutions, and local representatives, such as local politicians, village secretary/president, women and FCHVs.

The public health section at district level has sub-sections for different programmes such as family planning and FCHV programme, nutrition, child health, maternal and newborn health, HIV/AIDS, tuberculosis/leprosy, ORC, immunisation etc. Each sub-section is led by a district supervisor who is either a Staff Nurse (SN), HA, Senior Auxiliary Health Worker (Sr. AHW) or Senior Auxiliary Nurse Midwife (Sr. ANM). They are responsible to guide and ensure the implementation of programmes in each village by mobilising village based health institutions and their community wings: the FCHVs, ORCs and MGs.

In relation to newborn health, there is little clarity at the DHO about the roles and positions allocated to each section. The lack of clarity in roles and expectations was obvious at the commencement of this fieldwork when discussing newborn health with the district supervisor who provides the services and who plays the supportive role. The district supervisors develop plans, monitor and provide logistic and technical support to village health institutions. Finally, I came to know that a senior Auxiliary Nurse Midwife, in her role as a public health nurse was the district supervisor for maternal and newborn health programmes. The role of neonatal management keeps changing between different staff members.

4.3.2 Perinatal Health Interventions at District Level

Key interventions in perinatal survival are implemented by the DoHS 'safe motherhood' interventions introduced by the World Health Organization as discussed in Chapter Two. The government of Nepal initiated the Nepal Safer Motherhood Project (NSMP) in March 1997 (Support to Safe Motherhood Programme [SSMP], 2006).

Family planning, pregnancy, childbirth and postnatal care

At a district level, the main programmes include government's family health programmes such as the FCHV programme, family planning, antenatal care, safe birthing and emergency obstetric care (DHO, 2012). District hospital and peripheral health institutions are supposed to provide scheduled regular services such as family planning, regular antenatal, birthing and postnatal care of mothers and babies. Hospital and health institutions provide campaign based services such as childhood immunisation, family planning—usually Norplant and Voluntary Surgical Contraception, and reproductive health mobile camps such as screening camps for uterine prolapse. According to Nepal's Department of Health Services' annual report (2013/2014), Contraceptive Prevalence Rate (CPR) in Mugu is 33%, whereas it is 45% nationally (DoHS, 2014). The unmet need for family planning (two years postpartum) is 52% nationally, and is estimated to be even higher among rural residents (Mehata et al., 2014). As already discussed, FCHVs, MGs and ORCs are considered to be the foundation of the Nepalese community health system. They are supposed to engage and

mobilise families and communities to promote the health of women and children including newborns at home and communities.

Mugu is one of the first ten districts chosen to implement the Nepal Safe Motherhood Project (NSPM). At the national level, NSMP was financially and technically supported by the UK Department for International Development (DFID). The project aimed to reduce maternal and neonatal mortality by increasing access, service provision and innovative policy development. This was a seven-year-long intensive implementation from 1997 to 2004, technically facilitated by an international agency, the United Mission to Nepal (UMN) (UMN, 2017) at the district level in Mugu. The UMN is one of the oldest international agencies supporting the maternal and child health activities in the district for more than two decades. The district hospital started providing basic emergency obstetric care that included normal birthing, assisted birthing and management of complications during prolonged labour, eclampsia and retained placenta. This service became available 24/7 from 2006. Even though the Nepal Safe Motherhood Project (DFID, n.d) advocated the availability of regular caesarean sections (CS) and blood banks at the district level right from 1997, even today neither CS nor blood bank is regular and readily available. The districts did provide CS before, but did not continue with it throughout the year. While I was in the field, it was noticed that provision of CS had completely stopped at the hospital.

Birthing units

Mugu has already expanded its birthing facilities to nine of the 24 health institutions, all of them are reported to provide 24-hour birthing services by SBAs (DHO, 2012). Likewise, a woman coming to hospital or the birthing unit for antenatal and childbirth services should receive monitory travel incentives, and free maternity care as provisioned by the Safe Delivery Incentive Programme (SDIP) in 2005 and its amended versions (MOHP, 2007, 2013). This is in accordance with the national policy strategy to increase access to skilled care by encouraging women for institutional births, which is discussed further in Chapter Five.

Workforce training

Similarly, staff at DHO and health workers from village level health institutions including health volunteers have been provided with basic training to counsel women on birth preparedness and family planning; to distribute iron and anti-worm tablets to pregnant and postnatal women; and to refer and treat all under-five children including newborns for common illnesses. District staff are trained on a basic training package of Community Based Management of Maternal and Neonatal Illness and Community Based Management of Acute Malnutrition. According to the acute malnutrition reduction programme, nutritious flour is provided to pregnant women and all under-five malnourished children.

Recently, rural ultrasonogram scan training has also been provided to selected nurses from the district (Family Health Division [FHD], 2013). The rural ultrasonogram programme includes training of rural nurses/auxiliary nurses in ultrasound for early detection and management of pregnancy complications and foetal abnormalities (DoHS, 2014). Three nurses/auxiliary nurses and a medical officer from the district hospital were trained in the use of ultrasonogram from 2012, and they are supposed to frequently travel to the villages to run the USG scans at least during the first (within the first trimester) and the fourth (during the third trimester) antenatal visits. However, during five months of fieldwork in the district, I did not observe any nurse/medical officer visiting villages to do USG scans for pregnant village women.

After the introduction of the Skilled Birth Attendant policy (MOHP, 2006a), most nurses and auxiliary nurse midwives from the district have received SBA training. They are also provided with periodic refresher training to update their basic clinical skills and knowledge in maternal and newborn care. Whilst in the field, I participated at district orientations of the recently introduced Community Based Integrated Management of Newborn and Childhood Illness training (CB-IMNCI) organised by the Department (DoHS, 2015). This is a revised package of training currently under roll out throughout the district. It included training for health workers, including volunteers, to provide them with skills and knowledge to treat and manage health and wellbeing of under-five and newborn children.

Supports from non-governmental organisations

Health care at the district level is supported by a number of non-governmental agencies including UN agencies such as the United Nations Children's Fund (UNICEF), Food and Agriculture Organisation (FAO) and the World Food Programme (WFP). UNICEF has been supporting Community Management of Acute Malnutrition (UNICEF, 2012), and Maternal and Newborn Health (MNH), particularly towards strengthening of the birthing centres and supporting the DHO with training and capacity building to provide MNH services. Likewise, WFP has been supporting maternal nutrition and child health by providing seven kilograms of a nutritious fortified food package called super cereal to every pregnant and lactating women visiting health institutions since 2001 (Government of Nepal & WFP, 2012). Besides nutrition support, the aim of this programme is also to increase maternal and child health services from health facilities. Various other NGOs have also worked in Mugu district mainly assisting in water supply and sanitation, HIV and TB control, food security, and social mobilisation in the health sector.

4.3.3   Perinatal Mortality Records—Experience during Early Consultations

During the initial visit and informal discussion at the DHO, it was indicated that there are very few perinatal deaths occurring in the village. Staff at the DHO and the first village virtually denied neonatal deaths occurred in the villages. The purpose of reviewing the available records/register was to have an idea of the pattern of perinatal deaths being reported from the villages to the DHO.

According to the health information system in Nepal, every health institution, including health volunteers is provided with health report forms, the Health Management Information System (HMIS) form number 32 and 31, to be supplied each month. The forms report progress on utilisation of basic health services related to maternal and newborn care, neonatal deaths and stillbirths, and other morbidities, mortalities and health services. Altogether, only three neonatal deaths were reported in the district records from all the 24 villages for the period July 2014 to July 2015, including the Mugu district hospital. Although the hospital had a separate register, it was not well updated. The national annual reports of the DoHS were also reviewed to check if they had reports of the district's stillbirths and neonatal deaths. These records showed a total of 33 neonatal deaths, and 47 stillbirths reported in the last four years from 2010 to 2014, making up the sum total for all the 24 villages of the district.

These were still not village specific mortality reports. While I was reviewing these death reports, I knew from the impression of local staff that the reports were not accurate. Informal chats with some NGOs working in the field of maternal and child health to know if they had any village specific perinatal death records were not successful.

Staff working in the DHO, including the hospital, recalled deaths of women during and after birth, but they were not sure about neonatal deaths except guessing that there were one or two potential families with neonatal deaths. They did not even show interest about the stillbirths during the conversations, responded that they have not commonly heard of these in the villages. During these initial courtesy visits and chats, I did not hear from a single health worker about babies dying before *Chhaith*[9], or babies dying while the mother remained in *Gotha* (cowshed). *Gotha* is the ground floor used mainly to keep cattle, and store grass and firewood. Women in these villages give birth commonly in *Gotha*, and remain there from one to three weeks before entering the home. These consultations at DHO and village health facilities hinted that deaths have not actually been reported to the health system, and the reports prepared at village and district health level could not be trusted to be accurate.

Based on the perinatal deaths reported by interview participants, the villages have an invisible burden of high perinatal death rates. Box 4.1 gives a picture of mortality rates based on the number of deaths as reported by the women participants of this study (Appendix. 4).

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[9] *Chhaith* is a celebration on the occasion of birth of a newborn baby, usually celebrated on the 6th day after birth.

Extended perinatal mortality rate:	63 per 1,000 births
(Stillbirths plus neonatal deaths within the first month after birth)	
Perinatal mortality rate:	51 per 1,000 births
(Stillbirths plus early neonatal deaths within a week)	
Neonatal mortality rate:	44 per 1,000 livebirths
Number of estimated pregnancies (four years):	872
Number of estimated livebirths (four years):	752

Number of stillbirths and neonatal deaths in the villages based on interview participants reports in the present study

Stillbirths:	16 in the last four years
Neonatal deaths:	33 in the last four years
Early Neonatal deaths:	23 in the last four years

Note: the expected pregnancy and livebirths are based on 2013/2014 targets of the Department of Health Services, Ministry of Health and Population, Nepal; the 2013 estimates were multiplied by four to get the four years' estimates.

Box 4.1 Mortality rates and numbers in the two study villages (for four years preceding the interviews, based on voluntarily reported participant data)

Source: Fieldwork, 2015 (calculated based on participants' reported stillbirths and neonatal deaths in the two study villages)

It is very likely that the prevalence of perinatal mortality is underestimated. The villages have an ongoing unchecked mortality burden. For this study purpose, such a picture of perinatal deaths provides a perfect laboratory to explore factors in socio-cultural and health care contexts which have led to ongoing deaths in these mountainous villages.

4.4 Conclusion

To conclude, this chapter has provided a detailed description of the study site so that the readers are able to go through the findings presented in the subsequent chapters against the background of the present chapter. This chapter has also provided me with an opportunity to document his initial observations on the study setting. The next chapter aims to present a critical account of the key national policy strategies related to perinatal survival in Nepal.

CHAPTER FIVE

POLICY CONTEXT OF PERINATAL SURVIVAL IN NEPAL

The previous chapter discussed the various contexts in which the people studied in this thesis lived. These various contexts include the demography, the economy, gender roles, the fieldwork location, characteristics of the study villages and the local health care system. The objective of the present chapter is to present the key policy strategies employed by Nepal which have the intention of improving perinatal survival. This will assist to better understand the health care context and the community's experiences as end users of the health system. The chapter thus examines Nepal's national policies in relation to perinatal survival strategies. It commences with an overview of the historical development of national policies relevant to maternal and newborn health in general, followed by an explanation of a shift of focus, after 2000 towards improving newborn survival. Each policy document is separately reviewed, providing details of their processes, strategies and intended outcomes and the values and principles ingrained in them. Perinatal survival in the mountainous regions is discussed in the context of these policies to examine the gaps between policies and their implementation in practice, at the level of both the health care providers and health care users. The chapter highlights the extent to which policies have focussed on perinatal survival nationally, considering the distribution of perinatal deaths in the country. It also emphasises some of the existing strategies to tackle inequity in remote mountainous areas. Understanding the key policy values and strategies helps to identify the key medical and socio-cultural focus impacting perinatal survival.

A range of evidence has shown that innovation in policy directions and strategies impacts on the care and survival of babies and their mothers (Andersson et al., 2000; Caldwell, 1986; Costello et al., 2001; Lawn et al., 2005; WHO, 2014c). Chapter Two discussed the contribution made to reducing maternal and neonatal deaths through the employment of skilled midwives to support pregnancy and childbirth, the experience of the UK and Sweden in reducing neonatal deaths by basic primary health care measures, and the examples of reducing neonatal deaths by domestic and community measures utilising lay health mobilisers in South Asian countries. Analysis of health policies is crucial for understanding their influence on health systems and their focus and impact on population health (Van Olmen et al., 2012; Walt & Gilson, 1994). Hafner and Shiffman (2012) discuss the influence of health policy changes in strengthening health systems. They argue that the limitations of disease oriented initiatives, adverse effects of global health initiatives on local health systems, and bottlenecks in weak health systems have affected population health and equity. In this context, several authors (Black & Donald, 2001; Fisher, Baum, Macdougall,

Newman, & Mcdermott; Murray & Frenk, 2001) have indicated the need for increasing focus on examining the policy strategies, the policy processes and the use of evidence in policy formulation. Therefore, focus on policy review to understand the underpinning values and strategies is crucial for deriving insights into leveraging delivery of health care, in this case, pregnancy, birthing and postnatal services for perinatal survival in the mountain villages of Nepal.

The major international initiative emphasising perinatal survival includes the WHO's Every Newborn Action Plan (ENAP) (WHO, 2014b). The Millennium Development Goals (MDG) did not specifically emphasise perinatal survival. Neonatal survival was supposed to have been covered in the goal to reduce under-five mortality rate (MDG4). Later, the Sustainable Development Goal (SDG) specifically targeted to end preventable neonatal deaths by the end of 2030, highlighted it in its health related goal (SDG 3) (WHO, 2015a). Nepal has also gone through several policy changes, especially since 2000, thus a review of policy context seems vital in better understanding the regulating environment influencing perinatal care and its unequal distribution across the country.

This chapter reports on a review of all Nepalese government health policies relevant to perinatal survival which have been formulated after 2000 (Section 5.3). The documents reviewed in this chapter include national guidelines and policy and planning documents, all of which are still in current use. The review of policies facilitates an understanding of the Government's intention and focus of strategies to improve perinatal survival, and identify the strategies which are considered appropriate to impact on perinatal health care and survival.

Each selected policy document has been described briefly and reviewed with respect to its process, values, and health outcomes and strategic activities. The documents were reviewed utilising qualitative content analysis technique (Hsieh & Shannon, 2005), guided by an adapted framework (Box 5.1).

Besides presenting readers with policy strategies employed by Nepal at various levels which have the intention to improve perinatal survival, this review helps the readers of subsequent chapters to understand the health care context and parenthood experiences reported by people in the mountain regions.

5.1 Methods and Review Process

5.1.1   Document Identification and Selection: Web Search and Consultation with Experts

Having previously worked in the field of public health in Nepal for nearly seven years has helped me to utilise my existing professional network in identifying the most recent policy documents of the country. The methods used to identify policy documents included the following sources:

- Web search

The websites of the Ministry of Health and Population (MoHP): http://www.mohp.gov.np/, Nepal, and the Department of Health Services (DoHS): http://dohs.gov.np/ , were navigated. Programme progress reports were the main documents available on these websites. While searching these websites, staff working at district level and experts working at central departments and related international agencies were identified and approached through e-mail and face-to-face meetings. The staff members who were contacted worked in the DHO, Family Health Division (FHD), Child Health Division (CHD), and agencies working in the field of MNH such as UNICEF, One Heart Worldwide, Save the Children, and John Snow Inc. I also obtained information about documents related to perinatal survival from freelance consultants working in the area of MNH. As a result, a large number of annual reports of DoHS, progress reports of international agencies, policy documents, plans and guidelines were accessed (Figure 5.1). This web search and contacts with staff members helped to reflect on study objectives and consult experts working in MNH in government and non-governmental sectors of Nepal to identify the most appropriate and effective policies in shaping Nepal's perinatal survival.

Strategies for identification of policy related documents

Web search + face-to-face and Email contacts with professionals working in the Ministry of Health and Population, the Department of Health Services, and Non-governmental organisations in maternal and newborn health in Nepal

↓

Documents available

Six Annual Reports (2009 to 2014); Program Assessment Reports (related to birth preparedness and newborn care (2); National policy, plan and strategies (6); Implementation Guidelines (6); Training/program management guide (1)

↓

Policy selection

Six documents which were (i) currently in use (between 2000 to 2015) (ii) relevant to perinatal survival that describes the key country policy intent/strategies in primary health care settings, recommended by the experts involved in maternal and newborn health activities of government and non-governmental sector and (iii) published in English or Nepali language

Figure 5.1 Document review flow diagram

Source: Drawn by the author

Review process

Bowen (2009) discusses place and function of document review and analysis as a stand-alone qualitative research method, and as a complement to other research methods. Bowen talks about different types of documents including policy and programme related documents, and document analysis as a method suitable in case study, ethnography and grounded theory (Bowen, 2009). Document analysis is undertaken through an iterative process of skimming (superficial examination), reading (thorough examination) and interpretation, combining elements of content and thematic analysis (Bowen, 2009).

Document analysis also involves reviewing and synthesising qualitative and quantitative information. Hsieh and Shannon (2005) discuss three different approaches: conventional, directed and summative methods of undertaking qualitative content analysis. The key in this approach involves identifying text content and meaning behind it. The major difference in conventional, directed and summative methods is about how coding is practised. Codes emerge from text data in conventional approach, and from a prior coding framework (structure) as a guide in the directed approach. The summative approach involves more counting and comparison of key words or contents of specific interest in the documents, and therefore has a more quantitative orientation.

This review utilised a qualitative content analysis (directed approach) as suggested by Hsieh and Shannon (2005) guided by an adapted framework (Box 5.1) as an initial framework to code the contents of Nepalese policy related documents. The framework is based on insights from Walt and Gilson (1994) and Newman et al. (2006a, 2006b). Walt and Gilson talk about a triangular approach of examining policies to reform health sectors in developing countries. They identified the context that drives policy formulation, the technical content of policy, the process through which policy is formulated and implemented and the actors as individuals or groups (international, national and subnational) who have influence in policy making. Newman and colleagues derived a simpler, clearer and workable framework while reviewing the extent of the focus of Australian health policy related documents on social determinants. This helped as a guide to identify specific policy content areas such as objectives and outcomes, target groups, values, strategies, actors, and policy formulation processes as key questions while reviewing the documents. The adapted framework provided a guide on how to review specific elements of interest while reading the Nepalese documents. Coding was facilitated using NVivo (Version 10:00) software.

In this thesis, local voices of women and family members and health service providers constitute the main bulk of the study. The purpose of reviewing policy documents describing pregnancy, birthing and newborn care is to provide a policy context and to later discuss them against the local voices of the participants in the villages. To bring forward the context of how policy making evolved in Nepal, background papers and the previous versions of the documents have been also reviewed.

Box 5.1 Document review framework

Source: Adapted from Newman, Baum, and Harris (2006a, 2006b) and Walt and Gilson (1994)
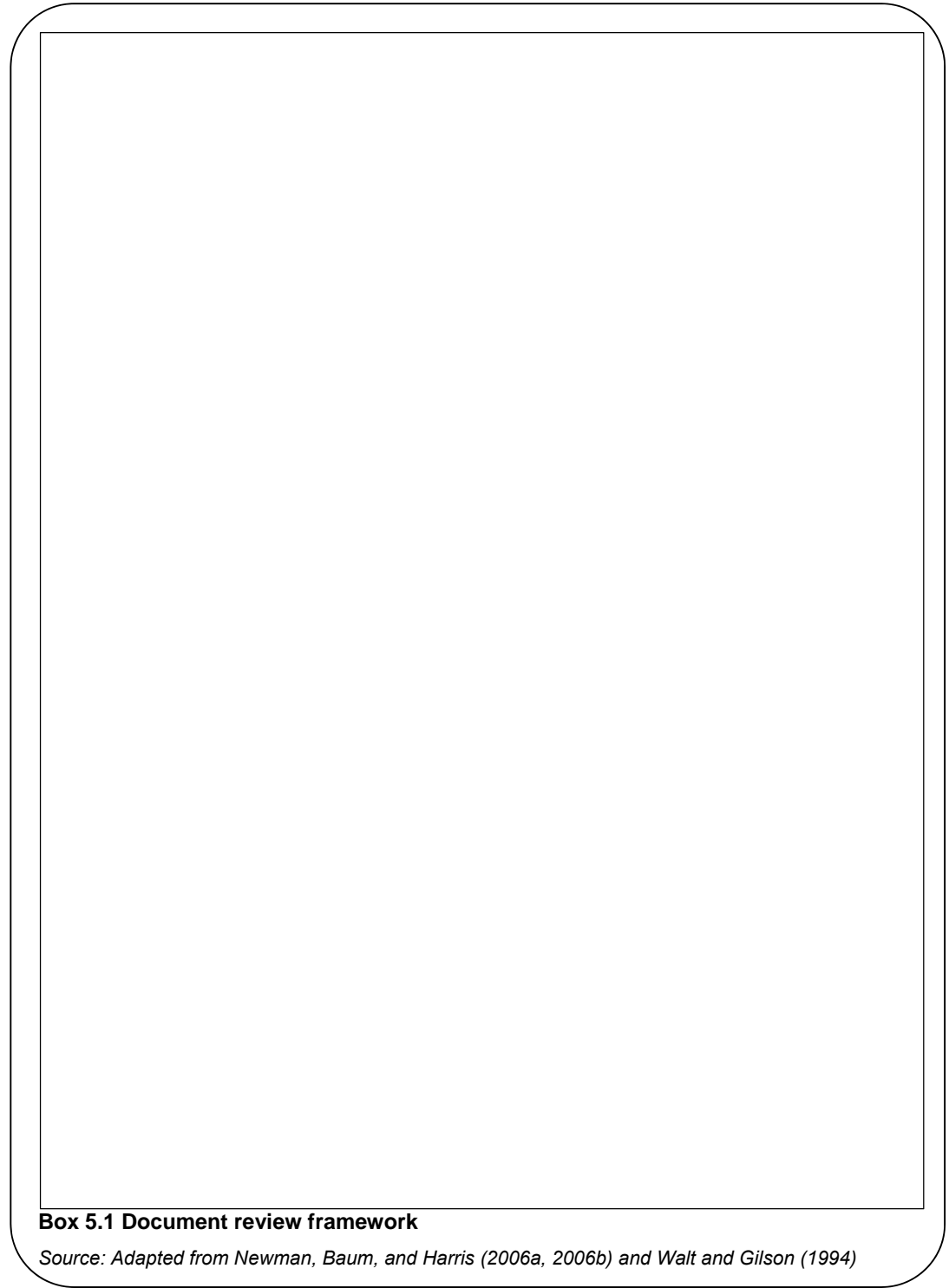
5.2 Perinatal Survival—Low Focus Before 2000

The document review showed that prior to 2000, perinatal survival did not become a priority area in any of the health policy documents in Nepal. The first ever programmatic response to high maternal and child mortality can be traced back to the Family Planning and Maternal and Child Health initiative in 1968 (Dixit, 2005, p. 137). After this, Nepal's policy response to address maternal and child health dates back to 1989 with the introduction of a voluntary network of FCHVs as the foundation of community health in Nepal (Glenton et al., 2010). Currently, there are over 50,000 FCHVs which the national health policy (Government of Nepal, 1991) considered a major pillar in improving health care for women and children, but their intention was mainly to address the ongoing high maternal and under-five mortality. Later on, in 1998, Nepal formulated the National Reproductive Health Strategy which included child health and safe motherhood as its components, and endorsed a basic standard of reproductive care from different levels of health facilities (MOHP, 1998). Yet, this strategy did not target perinatal survival explicitly. Its concern was on strategies to tackle the high prevalence of maternal mortality.

Safe motherhood became the government's priority programme, and Nepal developed its first Safe Motherhood Policy in 1993 (MOHP, 2006b) with the main and urgent focus to save women's lives during birth and within the postnatal period when the maternal and under-five death tolls in Nepal were known to be among the highest in the world (Garenne, Ronsmans, & Campbell, 1992; MOHP et al., 2012; Pradhan, Aryal, Regmi, Ban, & Govindasamy, 1997). Before 2000, early infant deaths did not come into policy discussions when the country was grappling with the high maternal and under-five mortality rates.

5.3 Policies after 2000—'Neonatal focused' but low priority in addressing stillbirths

After the collection of a wide range of policy and programme documents and consultation with key experts, six policy documents were identified as being appropriate for detailed analysis and review. These include:

- National Neonatal Health Strategy 2004 (MOHP, 2004b);
- National Policy on Skilled Birth Attendants, 2006 (Supplementary to Safe Motherhood Policy, 1998)(MOHP, 2006a);
- National Safe Motherhood and Newborn Health Long Term Plan (2006-2017) (MOHP, 2006b;
- Mother's Protection Programme-Implementation Guideline, 2013 (revision on Safe Delivery Incentive Guideline, 2007 and 2009)(MOHP, 2013);
- Maternal and Perinatal Death Surveillance and Response (MPDSR) Guideline, 2014 (MOHP, 2014) and;

- Community Based Integrated Management of Neonatal and Childhood Illness (Programme Management Module, 2015) (DoHS, 2015).

Survival of newborns did not become a major strategic priority until Nepal developed the 2004 National Neonatal Health Strategy (MOHP, 2004b). The guiding force behind Nepal's policy response to prevent neonatal deaths was the international initiative—the MDG-4 when Nepal realised the objective of improved under-five and infant mortality targets was not possible without addressing the high proportion of neonatal deaths.

Guided by the adapted framework as already stated (Box 5.1), the following sections detail individual documents including the content and focus, development process, the key values and motivations, and health outcomes and strategies adopted, which are considered to influence perinatal survival in the country. Drawing on key values and strategies, a summary table (Table 5.1) is presented at Section 5.4.

5.3.1   National Neonatal Health Strategy, 2004

The document and its formulation process

This strategic document (MOHP, 2004b) was endorsed by the Ministry of Health and Population, Nepal in 2004, and is still in use. The basis for the policy development was analysis of the neonatal health situation completed in 2002. This evidence comprised eight position papers on newborn health in Nepal, which were jointly produced by the Neonatal Health Working Group, WHO, Save the Children and USAID (MOHP, 2004b). It included evidence such as prevention and treatment of infections, birth complications, low birth weight, thermal protection, and supplements during pregnancy (MOHP, 2004b, pp. 8-9).[10]

Nepal's National Neonatal Health Strategy is considered as the first national strategic response explicitly focussing on newborns. The UN MDG 4 was also a driving force to prioritise neonatal survival. Although neonatal mortality was not specifically mentioned in MDG 4, the increasing proportion of neonatal deaths among the under-five deaths put pressure on international aid organisations and countries to prioritise newborn survival (WHO, 2015a). Internationally, the focus on reducing neonatal mortality became the central thrust of the WHO to achieve the MDG 4 and its target for reducing the under-five mortality rate (WHO, 2014c). At the national level in Nepal, formulating this policy became urgent when neonatal mortality constituted a major portion of infant mortality in the country. The policy document stated:

> …neonatal mortality has risen from 40% to 60% as a proportion of infant mortality. Further significant reductions in infant and child mortality rates will largely be dependent on reducing

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[10] The page number given in parenthesis refers to the page number of the National Neonatal Health Strategy, 2004. Page number/s in the quote has been cited similarly to the forthcoming documents in this chapter.

neonatal mortality (MOHP, 2004b, p. 2).

The National Neonatal Health Strategy was formulated to prevent neonatal deaths when more than 30,000 newborns were dying every year in Nepal (MOHP, 2004b, p. 2), which amounts to approximately three to four neonatal deaths every hour. The National Neonatal Health Strategy document was formulated when the situation was marked by a high proportion of homebirths, poor postnatal care, a poorly functioning referral system, and unattended obstetric and neonatal complications. Nearly 90% of women had homebirths, over half of which gave birth without the attendance of even a traditional birth attendant (MOHP, 2004b, pp. 2-3). The document also describes the context where about one-third of the women were not practising immediate and exclusive breastfeeding. The policy drew on the context that neither the community nor the health system understood what basic care would prevent newborn babies from any sickness and death.

> Appropriate care for the normal newborn[11] is neither widely understood nor practiced in the community or health system. Therefore, one of the sub-strategic objectives is to make the care of the normal newborn the foundation of interventions for improving neonatal health in Nepal (MOHP, 2004b, p. 3).

Normal newborn care meant the basic newborn care interventions such as immediate and exclusive breastfeeding, skin to skin contact with the mother, putting the baby in warm clothes, postponing bathing the baby for at least 24 hours, and taking care of the umbilicus. This also included education and counselling to prevent harmful practices, and early recognition of signs and symptoms of possible newborn infections (MOHP, 2004b, p. 2).

Values

It is stated at the forefront of the policy document that the then Secretary of the Nepalese Ministry of Health and Population acknowledged access to care and survival as the greatest right of every vulnerable newborn:

> Every vulnerable Nepali newborn has the greatest right to be taken care of and therefore we have to immediately invest resources to improve their health and survival (MOHP, 2004b, p. ii).

The policy has recognised the strength of addressing problems in mothers' and babies' health in a continuum. It highlights the need to address both maternal and newborn factors in order to prevent deaths in pregnancy and of newborn babies. The policy states:

> The mother and her baby should be treated as one entity and to be successful, any range of interventions that seek to prevent perinatal and neonatal deaths must address both maternal and neonatal factors (MOHP, 2004b, p. 1).

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[11] Care of normal newborn meant basic care for all newborn babies.

This policy emphasised the establishment of a linkage of care across home, community and health facility to promote newborn care and prevent deaths by setting interventions at domiciliary, community and health facility levels. Although it acknowledged the problems associated with accessing remote and disadvantaged areas, it did not specifically state any regional/ecological specific strategies. Hence, the significantly high neonatal death rates in the mountain areas are not specifically highlighted nor are mountain specific strategies outlined to address them.

Health outcomes and strategic activities

The main aim of the National Neonatal Health Strategy, 2004 is to contribute to the reduction of neonatal deaths (MOHP, 2004b). It sets strategic objectives to promote healthy newborn practices and to improve the quality of preventive and curative care from communities and health facilities (MOHP, 2004b, p. 3). The policy considered a set of evidence based and proven interventions from across the world such as normal newborn care with Kangaroo Mother Care (KMC), breastfeeding, and treatment of infections. KMC is care of the baby in the kangaroo position, involving both parents by turn, aiming to ensure early, continuous and prolonged skin to skin contact, and mother and baby bonding (WHO, 2003a). This policy sets its direct focus on addressing complications of mothers and babies for immediate impact:

> …proven interventions addressing causes of maternal and neonatal complications at family and community levels will be the primary focus for immediate impact. These interventions will require the establishment of a chain of care linking families and communities with the health system (MOHP, 2004b, p. 2).

The policy states that the key impetus to set priority interventions was to address Nepal's high proportion of homebirths with nearly 90% of women giving birth at home without SBA. The main policy intention remained to promote health facility births and prevent neonatal deaths during or shortly after birth. This policy also devised strategies to institutionalise provision of newborn care within Nepal's health care system. To do so, the policy set neonatal care services at four different levels: home/community level, primary health care level, district hospital level and zonal, regional and central hospital level (p. 12). It sets forth five key intervention areas (MOHP, 2004b, pp. 4-7).

1. Policy level interventions: aimed to set policy strategies on birth and death registration and to institutionalise the Family Health Division (FHD) as an institutional apex body to lead the newborn care programme, and to ensure gender equality in neonatal care.
2. Behaviour change communication (BCC): talks about introducing targeted BCC activities for mothers, husbands and mothers-in-law by mobilising health workers, traditional birth attendants and FCHVs. It emphasised knowledge transfer around danger signs during pregnancy, birth and the postnatal period.
3. Strengthening health service delivery: the key focus here is on promoting births attended by SBAs, and postnatal visits of mother and baby. This policy set activities at the family/community level focussing mainly on the BCC messages regarding birth preparedness,

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normal newborn care, danger signs, and reducing harmful practices by mobilising FCHVs and non-formal care givers such as Traditional Birth Attendants (TBAs) and mothers groups. At this level, it also emphasised treating common infections, appropriate referral, and notification of birth and death by community health workers. At the health facility level, it focussed on antenatal, birthing and postnatal care, recognition and treatment of sick newborns by SBAs and other health workers using standard protocols and algorithms.

4. Strengthening service management: included action to ensure supplies and appropriate logistics; and

5. Research: focused on the ongoing surveillance on the quality of care provided in community and health facilities, and verbal autopsies of perinatal deaths at community level. Verbal autopsy is a method used to ascertain the cause of death by interviewing next of kin or care giver, used mainly to identify causes of perinatal, infant and maternal death at population level (WHO, 2012).

The policy recommended these five key interventions for achieving the strategic objectives of improving healthy newborn care practices and improving quality of neonatal care.

The policy discusses the establishment of a well-functioning referral mechanism for sick newborns, care for non-sick LBW babies, and management of newborn infections with appropriate antibiotics in village health facilities. At the hospital level, it included additional activities such as management of obstetric and newborn complications, intravenous drug administration, perinatal death audits and training and supervisory activities of staff working at peripheral health facilities.

5.3.2   National Policy on Skilled Birth Attendants, 2006

The document and its formulation process

Nepal introduced a Skilled Birth Attendants (SBA) policy in 2006 (MOHP, 2006a) targeting the high prevalence of maternal and neonatal mortality. The SBA policy is supplementary to the Nepal Safe Motherhood Policy, 1998. The National Safe Motherhood Long Term Plan 2002-2017 envisioned delivering maternal and newborn care at all levels of health care (MOHP, 2002). This SBA policy is an outcome stated in the long-term plan. The Ministry of Health and Population established a policy advisory group in May 2006 which then came up with the SBA policy, 2006. Nepal considered formulation of this policy imperative in the context that only 13% of women were attended by health workers during childbirth. Maternal and Child Health Workers (MCHW) and ANMs were identified as being ineffective in reducing the number of maternal and neonatal deaths (MOHP, 2006a, p. 2). One of the main gaps noted in the MCHW and ANM is the lack of professional competency to provide maternal and newborn services, particularly in managing obstetric complications. The SBA policy is set to address the lack of skilled attendants at birth and also to overcome the poor referral system and lack of access to life-saving emergency obstetric care to women in villages across the country.

Values

Apart from producing professionally competent SBAs, the policy emphasised the importance of women-friendly care during pregnancy and childbirth in a culturally sensitive and affordable manner. The policy stood on the evidence that improving access to skilled attendants at birth prevents a large proportion of maternal and neonatal deaths, as discussed earlier in Chapter Two. Citing the Nepali context, where the majority of women are still giving birth at home, the policy explicitly prioritised health facility births and treatment of obstetric complications that can potentially lead to deaths of mothers as well as babies. Although it did not specifically mention the mountainous regions, it highlighted that priority be given to the poor and underserved areas.

> …it is important to encourage women to deliver in facilities with skilled attendants with access to Emergency Obstetric Care (EmOC). This will require 24 hours a day and 7 days a week, women-friendly services that are culturally sensitive and affordable to all families, especially those in poor and underserved areas (MOHP, 2006a, p. 1).

Health outcomes and strategic activities

The policy adopts the WHO definition of SBAs with 27 core skills and abilities (MOHP, 2006a).

> An accredited health professional such as a midwife, doctor or nurse who has been educated and trained to proficiency in the skills needed to manage normal (uncomplicated) pregnancies, childbirth and the postnatal period and in the identification, management and referral of complications in women and newborns (MOHP, 2006a, p. 3).

However, up to the first five years after the SBA policy, a working definition of SBA was seen as:

> Those physicians, gynaecologists and obstetricians and other health personnel with at least 18 months training in maternal and child health will be considered as skilled birth attendants. (MOHP, 2006a, p. 4).

The core skills and abilities mentioned in the policy document included: effective communication skills to provide women-centred care during pregnancy, birthing and the postnatal period in a partnership with women and family members; assistance during birth; identification and management of possible complications; appropriate referral as required; education and counselling about breastfeeding; care of baby; and supervision and support to other health workers and non-formal care givers (MOHP, 2006a, pp. 11-12). This policy sets a national target to increase SBA attendance at birth to at least 60% by 2015 (MOHP, 2006a, p. 2), which is yet to be achieved (until 2017) at the national level in Nepal. It will take much longer to achieve this target in the country's mountainous areas.

The strategies on SBA focused mainly on two aspects: (i) upskilling SBAs by in-service training and incorporating SBA skills in pre-service curricula of ANM, Staff Nurse (SN) and doctor training; and (ii) deployment of SBAs to health facilities (MOHP, 2006a, pp. 7-9). Regarding the latter strategy, the policy highlighted the need for creating an enabling environment for SBAs working in the periphery by ensuring supportive supervision and supplies, effective partnership in the work

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environment with other health workers, accommodation and support from local facility management committee. The policy document states:

> Maternal and neonatal health outcomes will only be improved if the SBA is supported by: strong referral back-up by a district health team, including supportive supervision; effective partnerships with other health workers such as the HA, AHW, MCHW, VHW, health volunteers (FCHV), other non-formal care givers like TBAs, and the community; availability of essential drugs, supplies and equipment; adequate systems for communication and referrals, safety and security, and sufficient incentives to compensate for the professional and social isolation that is often a reality of remote postings (MOHP, 2006a, pp.7-8).

The policy intends to ensure availability of 24-hour emergency obstetric care in a close partnership with health workers other than SBAs. The then secretary of the Ministry of Health and Population highlighted this in the opening remarks of the document:

> The SBA will work in close partnership with other essential health care providers at community level and be supported and guided by a strong District Health Team that has the capacity to deal effectively with emergency obstetric complications 24 hours a day, 7 days a week (MOHP, 2006a, p. I).

To ensure 24-hour service, the policy also envisaged expanding birthing units (centres) in health facilities, and encouraged NGOs and communities to establish community based birthing units at local level (MOHP, 2006a, pp. 8-9).

5.3.3 National Safe Motherhood and Newborn Health Long Term Plan (2006-2017)

The document and its formulation process

The purpose of National Safe Motherhood and Newborn Health Long Term Plan (NSMNHLTP) (2006-2017) is to increase healthy practices and to improve the quality of care for both mothers and their newborn babies. The document was prepared in consultation with both government and non-governmental stakeholders at the central level. The formulation of the document evolved through three stages: (i) preparatory meeting in November 2005; (ii) first workshop in January 2006 after consultants' review of existing policies and gaps leading to the development of a background paper for revision; and (iii) the second workshop in March 2006 which set the detail of outputs and activities across various thematic groups.

This document is the second version of Nepal's National Safe Motherhood Long Term Plan (NSMLTP) (2002-2017). This version incorporated responses to some of the urgent changes at the time such as the MDGs and a focus on newborn health, increasing the numbers of SBAs at births, and the Health Sector Strategy: An Agenda for Reform (MOHP, 2004a). The purpose of the reform strategy was to ensure a system that provides access to essential health services to the poor and vulnerable population. The reform also aimed to develop capacity of local bodies for participatory and accountable management of health facilities and to build partnerships and mobilise NGOs and the private sector in health service delivery. The NSMNHLTP also paved a systematic way to implement legalisation of Comprehensive Abortion Care (CAC), and to introduce prevention of

mother to child transmission of HIV through hospitals and health facilities in Nepal. This latest version was produced also to incorporate the first ever produced MDG country progress report 2005 (Government of Nepal, 2005) which came after the first long term plan (2002-2017) (MOHP, 2002). Compared with the first version, this has strongly prioritised SBA mobilisation to reduce both maternal and newborn mortalities in the country.

Values

The NSMNHLTP (2006-2017) is the first national plan to have a strongly stated approach based on equity, social inclusion and rights in providing maternal and newborn care across its outcomes and activities. Equity-based, women centred, and multi-sectoral approaches have been identified as underlying values of this policy document. The document strongly upholds the equity principle, particularly in access and utilisation of health services for newborn babies including safe motherhood services among the needy, but it does not yet specifically identify 'mountainous regions' as its strategic focus. The long term plan highlighted the need of financial safety nets for the poor and socially excluded groups.

> Equity issues in access and utilisation of safe motherhood and newborn health (SMNH) services are not mentioned in the original NSMLTP and are of critical importance if the most needy members of society are to be targeted and the MDGs achieved (MOHP, 2006b, p.2).

This document has acknowledged the role of multiple sectors to ensure equity and access to care in MNH. The document has viewed MNH not merely as an issue for the health sector, but for other sectors as well.

> Since safe motherhood and newborn health are not purely health issues, they warrant a multi-sectoral approach and the role of other sectors is particularly important in enhancing access and promoting equity (MOHP, 2006b, p.1).

The plan also duly recognised the needs of women to be understood in complex social contexts:

> The needs of women are treated as paramount throughout the NSMNHLTP, not simply as individuals, but as members of families and communities functioning within complex relationships and social expectations (MOHP, 2006b, p.4).

Health outcomes and strategic activities

The plan aims to improve maternal and newborn mortality especially among the poor and socially excluded groups, yet, it did not separately identify the mountainous region. The key outcomes that this plan prioritised are: promotion of facility based births, attendance at births by SBAs, and reaching the met need for emergency obstetric complications and caesarean section. At least 15% of pregnant women are estimated to experience obstetric complications, and at least 5% of them are estimated to need a CS (WHO, 2009b). Accordingly, it has set targets to increase the proportion of health facility births, births with SBAs, and the proportion of women meeting their needs to manage obstetric complications and caesarean section.

The plan has set eight strategic outputs to ensure progress in the health of mother and babies. These are: equity and access; delivery of quality maternal and newborn care; public private partnership; decentralisation; and human resource development—mainly focussing on SBA training; information management; physical asset management and procurement; and finance such as financial safety nets/vouchers to increase health care utilisation. This has considered equity and access as an approach to ensure utilisation of maternal and newborn care in communities by empowering individuals, groups and networks with the maternal and newborn care related BCC messages. To promote maternal and child health, the plan emphasised the implementation of participatory approaches and promotion of birth preparedness and non-discriminatory interpersonal communication between providers and clients. In doing so, the plan emphasised the need to understand local knowledge about the contexts of maternity and newborn care.

> Activities will advantageously use local knowledge, perceptions and values, relevant traditional practices, preferences and beliefs to enhance knowledge and awareness and will be sensitive to conflict issues (MOHP, 2006b, p.7).

The plan identified access in a broad sense that considers not only the physical and financial access but also the cultural and behavioural aspects of service providers so that women can make the best use of the available health care during pregnancy, birthing and after birth.

> Access embraces financial, institutional and infra-structural factors including, but not limited to, funding, transportation and education. It also relies upon positive and welcoming service provider attitudes, trust, honesty, responsiveness, accountability and quality service delivery both at established facilities and through outreach programmes (MOHP, 2006b, pp. 7-8).

The service delivery outputs of the plan included delivery of quality maternal and newborn care comprising, antenatal, birthing and postnatal care. It also emphasised reaching socially excluded groups. Essentially, the plan has prioritised strengthening of service at a health facility level. However, it also acknowledges the need for delivery of care at family and community level through home visits and mobilisation of ORC (MOHP, 2006b, p.9). It has also encouraged the 24-hour availability of skilled staff and district specific strategies to increase service access in remote areas.

> At service level, efforts to improve the effectiveness of the system will focus on ensuring 24-hour availability of skilled staff with essential drugs and equipment, good community and inter-facility linkages and feedback systems to promote further improvements. Remote areas present an even greater challenge and require additional focused efforts, which will be covered by district specific strategies (MOHP, 2006b, p.10).

With regard to public private partnerships, the plan sought increasing involvement of NGOs, private sector hospitals and academic institutions in maternal and newborn care activities. In decentralisation, the plan sought to ensure planning and supervising capacity with local government, that is the DHO and health facilities. Likewise, as a financial strategy, it aimed to ensure financial safety nets for the poor and socially excluded. Regarding the information system, the plan highlighted collection and use of data according to ethnicity, caste and wealth. It also identified the need to supplement quantitative information by exploring qualitative information to

increase the reliability of the information, and to collect information about maternal and newborn deaths by joint collaboration of health facilities and FCHVs. This would enable a better understanding of MNH.

> To supplement quantitative data, additional information will be collected through qualitative studies using a range of different tools, such as key informant monitoring. Exercises to verify data and increase its reliability will be designed and implemented. Information will be collected for maternal and newborn deaths from health institutions in collaboration with FCHVs (MOHP, 2006b, p.13).

5.3.4 Mother's Protection Programme, Implementation Guideline, 2013

The document and its formulation process

Mother's Protection Programme, Implementation Guideline, 2013 (MOHP, 2013) is a successive revision of the previous guidelines of the Safe Delivery Incentive Programme (SDIP). The SDIP was first introduced in 2005, revised in 2007 and subsequently evolved as the Mother's Protection Programme, Implementation Guideline, 2009. This latest 2013 guideline was formulated by a working committee involving both district and central level experts from relevant sections and departments. The amendment to the 2009 version was felt necessary to set criteria for types of health facilities to be provided with financial incentives, and to highlight that women are given first priority to have this financial incentive before the health facility and providers themselves. This incentive is to encourage the health facilities to ensure quality birthing services and to cover basic expenses including drugs and logistics whereas the purpose of giving the monitory incentive to providers is to encourage them to ensure their 24-hour availability to assist women during births.

The SDIPs (2005 and 2007) provided incentives to women to encourage them to attend facility births. However, advancing further on the SDIP, the Mothers Protection Programme expanded free maternity care through government health facilities and hospitals, and community and teaching hospitals from 25 low HDI remote mountain districts to all facilities across the country in order to: (i) reach the MDG maternal and child health targets; and (ii) ensure the right to health as a fundamental constitutional right of every citizen in accordance with the provision of Nepal's interim constitution 2006 (MOHP, 2013, p. 4).

Values

Special attention has been given to monetary incentives for women to attend health institutions for pregnancy check-up and childbirth. It has explicitly encouraged birth to be attended by SBAs in health facilities (birthing units). On the other hand, it has reduced providers' incentives to attend homebirths to Nepalese Rupees (NRs) 100 (about AUD 0.8) from the previously provided NRs 200 (about AUD 1.6). The document also envisaged a partnership approach in providing maternity and newborn care with private, teaching and community hospitals (MOHP, 2013, p. 4).

Health outcomes and strategic activities

The document aims to contribute to the reduction of maternal and newborn deaths. The key strategy is to increase births attended by SBAs, with an emphasis on births in health facilities. The SDIP guideline 2005 and the first amended version of it (SDIP 2007) provisioned financial safety nets for improving access to maternity care. The amended 2007 version explicitly identified free maternity care in all 25 low HDI remote mountainous districts. This policy also set a slightly higher travel incentive (NRs 1,500, about AUD 19) to cover travel expenses from home to the health facility birth for women in the mountainous regions (MOHP, 2007). It sets NRs 500 (about AUD 6) to women in the plains areas and NRs 1,000 (about AUD 12) to women in hilly districts. This incentive amount covers at least their one time travel expense and a day's meal. For a daily labourer, 6 to 19 AUD is approximately a day's earning. This is reasonable considering that women in the mountainous areas have to walk comparatively a longer distance to attend health facilities. Further, emphasising birth in health facilities, this policy provisioned that women will receive additional monetary incentive for antenatal check-ups only if they attend health facilities for the all recommended four visits plus attend health facility for childbirth.

> Mothers who came for four focused antenatal visits and also gave birth in a health institution, will be provided NRs 400 from pregnancy and delivery [childbirth] incentive during discharge from health institution (MOHP, 2013, p. 6).

The guideline also requires health facilities to do public auditing of women provided with incentives and provide the incentive immediately upon discharge after birth. With regard to facility based incentives, this guideline provisioned the unit cost within defined health facilities as follows:

- NRs1,500 (about AUD 19) for a normal birth in hospitals (>25 beds);
- NRs 1,000 (about AUD 12) for hospitals and other health facilities having fewer than 25 beds;
- NRs 3,000 (about AUD 37) for any birthing units or hospitals managing a complicated birth; and
- NRS 7,000 (about AUD 87) for each Caesarean Section.

These incentive rules also apply to women who visit health facilities after obstetric complications at homebirths (MOHP, 2013, p. 14). This provides women attending health facilities who require referral to higher centres. The guideline has set financial incentives for service providers to be divided equally by their team, including any support staff, who contributed during birth as a part of a team.

The guideline has expanded the concept of birthing units (MOHP, 2013, pp. 23-25) by setting specific criteria. These criteria included physical infrastructure and space with one separate birthing room, equipment, accommodation for SBA, 24-hour presence of an SBA including support staff, good referral network, friendly behaviour to women and their visitors, and the respect of a woman's privacy while giving birth.

An improved reporting system is also highlighted in the guideline. Health facilities are obliged to develop monthly reports on obstetric complications managed by the facilities (MOHP, 2013, p. 20). The new obstetric reporting form included reporting to the district and central department of newborn deaths, stillbirths and babies resuscitated for asphyxia management. To encourage births and deaths registration, the guideline made a provision for a provider incentive for homebirths only upon submission of the report of either the birth or the death registration of the baby.

5.3.5   Maternal and Perinatal Death Surveillance and Response (MPDSR), Guideline 2014

The document and its formulation process

> Maternal and Perinatal Death Surveillance and Response is a form of continuous surveillance process that links health information system and quality improvement processes from local to national levels. It includes routine identification, notification, quantification and determination of causes and avoidability of all maternal and perinatal deaths, as well as the use of this information to respond with actions that will prevent future deaths (MOHP, 2014, p. 2).

The Maternal and Perinatal Death Surveillance and Response (MPDSR) evolved from the Maternal and Perinatal Death Review (MPDR). The MPDR was initiated after first implementing the Maternal Death Review (MDR) which dates back to 1990 when Nepal's Family Health Division (FHD) first implemented it in a national hospital in Kathmandu with technical support from the WHO. The PDR component was introduced in 2003, and then implemented for the first time in six Nepalese hospitals. By the year 2012, the MPDR expanded to 21 hospitals in the country. In 2013, after revision of the PDR tool, this expanded to 42 hospitals, and evolved into the MPDSR guideline. Internationally, Nepal's MPDSR is in accordance with the UN Global Strategy for Women's and Children's Health and the Commission on Information and Accountability (CoIA) (MOHP, 2014, p. 4). This document is proof of Nepal's Ministry of Health and Population's attempt to implement locally appropriate and viable mechanisms to reduce maternal and perinatal deaths. The two key objectives of the document (MOHP, 2014, pp. 4-5) are: "(i) To provide information that effectively guides immediate as well as long-term actions to reduce maternal mortality at health facilities and community and perinatal mortality at health facilities; and (ii) To count every maternal and perinatal death, permitting an assessment of the true magnitude of maternal and perinatal mortality and the impact of actions to reduce it".

Values

This guideline acknowledged the value of the life of every mother and every baby. The review of every maternal and perinatal death occurring in health facilities has been considered as a self-reliant and sustainable approach to the improvement of health care for women and their children. The guideline clearly identified the urgency to prevent every maternal and perinatal death: "MPDSR underlines the critical need to respond to every maternal and perinatal death, so that the information obtained from that death might be acted upon to prevent future deaths" (MOHP, 2014, p. 3). It further adds "every death can provide information that can result in actions to prevent

future maternal and perinatal deaths" (MOHP, 2014, p. 25). However, it has not said anything specific to eco-regions such as to respond to high death rates in the remote mountainous regions of the country.

Health outcomes and strategic activities

Strategically, this document aims to link the information system to quality improvement processes at a health facility level. This is to guide and support health workers and to enable real-time monitoring of deaths and assessment of interventions employed. The document's two main focusses are on the notification of every death, and their review for further actions to prevent future deaths.

> The notification of every maternal and perinatal death also permits the measurement of maternal mortality ratios and perinatal mortality and the real-time monitoring of trends that provide countries with evidence about the effectiveness of interventions (MOHP, 2014, p. 3).

Although the above statement identified notification of every death, it has not prioritised notification and review of every perinatal death. Maternal death occurring both at health facilities and in communities are notified and reviewed; whereas, for perinatal deaths this is aimed only at the health facility level. This means that a considerable number of deaths occurring in communities, and more so in the remote mountainous areas which still have high perinatal deaths, might be missed.

> MPDSR also stresses on the need to collect data on maternal deaths in the facility as well as community and perinatal deaths in the health facility and use the information to give a clear picture of the weaknesses in the health-care delivery system (MOHP, 2014, p. 4).

The document's main intention is to ensure that remedial measures are taken timely at health facilities to prevent ongoing perinatal deaths. The MPDSR has not as yet reached the hospital level in the study district. There is no death review mechanism except a routine reporting requirement of perinatal and maternal deaths in the government's regular reporting system through Health Management Information Systems (HMIS).

MPDR process:
- This policy guideline has recommended the MPDSR cycle comprising five key elements as shown in the diagram (Figure 5.2). The case identification involves notifying any maternal deaths in the health facility and community, and perinatal deaths in a health facility.
- The policy guideline has proposed a committee for the review of maternal and perinatal death at each health facility level. At the district level, the committee comprises chief of the DHO, statistician, medical doctor, public health nurse and invited members from the district's RHCC and a member from any other relevant line agencies. The committee did not explicitly include anyone from parents/family.

- The review tool comprised structured questions focussing dominantly on clinical details of the deceased baby, possible causes of deaths, and the health care procedures followed for treatment.

Figure 5.2 Cycle of Maternal and Perinatal Death Surveillance and Response

Source: Drawn by the author based on the review of policy documents
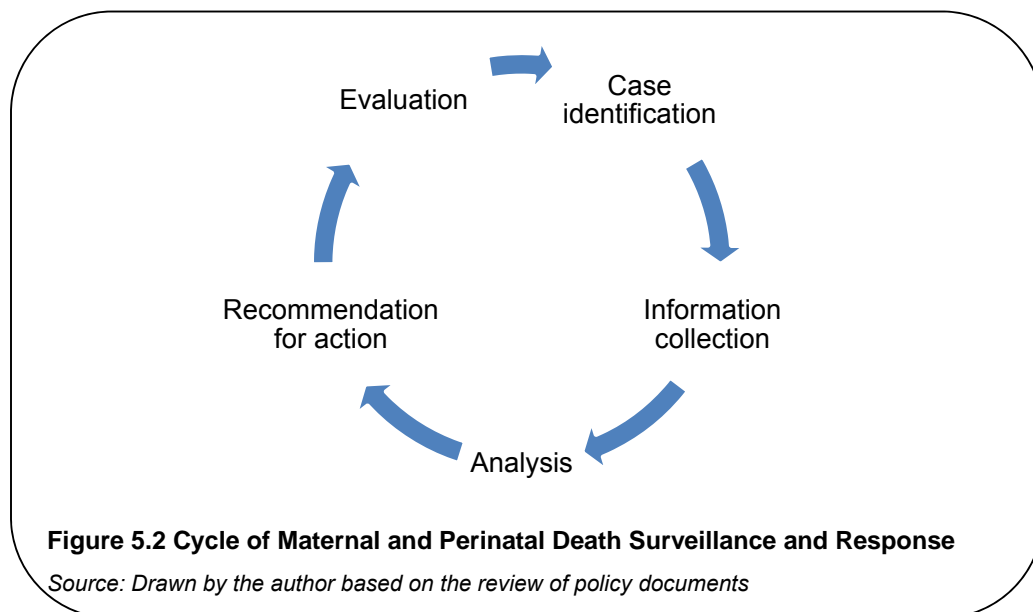
- At the district level, regarding the review process, any suspected maternal or perinatal death is notified (maternal death within 24 hours and perinatal death within 72 hours) by the attending service provider to the district level MPDR committee. For a perinatal death, the attending service provider fills the PDR form, and PDR review is scheduled once a month.
- At the local health facility level, once the local committee reviews a case (maternal or perinatal death), the report is then forwarded to the district committee where all cases coming from local health facilities are further reviewed and recommendations made for action.

5.3.6 Community Based Integrated Management of Neonatal and Childhood Illness (Programme Management Module), 2015

The document and its formulation process

Community Based Integrated Management of Neonatal and Childhood Illness (CBIMNCI, Programme Management Module, 2015) describes the most recently revised package of key interventions to address newborn survival in Nepal. The key objective is to reduce newborn and under-five morbidity and mortality by managing health problems and promoting immediate care.

This programme package is considered as the most recent update of Nepal's continuous efforts for the survival of newborn babies including that of under-five year old children. It focused on the provision of improved care by health service providers including trained health volunteers in local communities.

This packaged CBIMNCI programme is the result of lessons learned over the last three decades from a range of previous interventions (DoHS, 2015, pp. 6-7):

- Control of Diarrhoeal Diseases (CDD) in 1983;

- Acute Respiratory Infection (ARI) control programme which started in 1987 with the focus of controlling ARI and pneumonia among under-five year old children;

- Community Based Acute Respiratory Infection Control (CBAC) control programme, among under-five year old children;

- Integrated Management of Childhood Illness (IMCI) from 1997 with the key focus on managing five major killer diseases of under-five year old children. The five major killer diseases included Malaria, Malnutrition, Measles, Pneumonia and Diarrhoea;

- Community Based Integrated Management of Childhood Illness (CBIMCI), bringing IMCI to female community health volunteer's level for treating and referring under-five year old children; and

- Community Based Newborn Care Programme (CBNCP) from 2007, thus specifically focusing on newborn care at home, community and peripheral health facilities.

The CBNCP comprised a package of key interventions to be delivered from health facilities and by health volunteers. It included promotion of facility births, social mobilisation for behaviour change mainly through FCHVs and mothers groups; postnatal check-up visits for mothers and newborn babies; management of possible bacterial infections such as diarrhoea and pneumonia; management of LBW babies mainly by keeping them warm like practising kangaroo mother care; prevention of hypothermia; and management of asphyxiated babies. This 'CBNCP' package has been revised and now in its most recent form is known as CBIMNCI.

The CBIMNCI still emphasises the newborn component, included the interventions of CB-NCP, and has also integrated the IMCI for effective management of all under-five children's problems as a single package from health facilities. Therefore, this document is the result of lessons from the field. It came into this form as a continuous collaboration of government as well as non-governmental actors— a series of joint meetings of the child health partners and working groups.

Values

This programme management module emphasises reaching care to the disadvantaged and marginalised groups and the provision of quality care through public-private partnership. Yet, it does not identify any specific strategies to reach them. The document, despite the 'community-based' notation in its title, still focuses mainly on promotion of facility based births and strengthening the quality of care in health facilities. Health facility has been a key focus, and for the near future, it also envisions a new programme entitled Facility Based Integrated Management of Neonatal and Childhood Illness (DoHS, 2015, p.11). The focus has been on strengthening the capacity of health facilities to manage and treat newborn complications such as infection, asphyxia and LBW. It has added a component which describes treatment of baby's cord infections by using an antiseptic ointment, chlorhexidine. The package does not consider management of asphyxia as

local health volunteers' job responsibility. However, asphyxia management by the health volunteers was considered a key task in the CBNCP package.

Health outcomes and strategic activities

The CBIMNCI has been designed to reduce newborn and under-five child morbidities and mortalities by promoting essential newborn care and addressing key health problems of newborns and under-five children. This module considers the lessons from the CBNCP package, and merges the package with IMCI, thus making a single integrated package for managing newborn and all under-five children's health problems. Generally, the document discusses improving the quality of newborn care; reaching care to communities; reaching the marginalised and disadvantaged; strengthening the supply system; continuing research and investigations for programme improvement and positive behaviour change at homes and the community; and community participation in newborn care (DoHS, 2015, p.12). However, it has not specifically discussed how to reach the marginalised population, and what kinds of research and investigations it will focus on. In addition, despite being the most recent strategic module, the document has no emphasis on stillbirths or strategies to tackle this problem.

This document is based on the revision of the previous CBNCP programme. Despite the monitory incentives, the CBNCP programme did not find FCHVs effective in contributing to newborn care as previously expected. Many lacked the confidence to manage asphyxiated babies in communities (DoHS, 2015, pp. 9-10). It was identified that only 1.5% of the total infections were managed by FCHVs, the proportion of managed asphyxiated babies is lower. They were also found ineffective in utilising other basic skills such as using a thermometer to read the baby's temperature, and in classifying LBW babies. FCHVs misclassified over two-thirds of LBW babies, which resulted in the lack of a clear picture of very LBW and LBW babies. The programme considered any baby below 2,000 grams as very LBW and those in between 2,000 and 2,500 grams as LBW. The programme assessment showed the lack of trust in FCHVs as a reason for women to bypass health services. The assessment identified that only 11% of mothers contacted FCHVs when their babies fell sick. Such weaknesses became the rationale for merging CBNCP with IMCI, and thus introducing CBIMNCI. Besides this, the document states that the merging of CBNCP and the IMCI was technically feasible and economically less burdensome on the government (DoHS, 2015, p. 9).

This new package included mainly the following key health care services for newborn care: promotion of health facility births, essential newborn care and regular postpartum check-ups for mother and newborns, management of infection, management of low birth weight baby, and assessment and management of hypothermia. The package also envisioned developing one to two birthing centres (units) per district to ensure quality referral care for newborns with complications.

5.4 Summary

A brief summary table with key strategies and values is presented in Table 5.1

Table 5.1 Summary of key values and strategies

Key values (approach, underpinning principles)	Strategies (strategic interventions)
National Neonatal Health Strategy, 2004	
• *Access to care and survival as the greatest right* of every vulnerable newborn • Mothers and babies' *health in a continuum from pre-pregnancy to postnatal* • A *linkage of care across home, community and health facility* • *Gender equality in newborn care*	• Focus on proven interventions addressing causes of maternal and newborn complications • Promotion of health facility based births and preventing newborn deaths during the process of birth or shortly after birth • Institutionalisation of provision of newborn care from Nepal's health care system: (i) home/community; (ii) primary health care; (iii) district hospital; (iv) above the district hospital at zonal, regional and central hospital level • Sets forth five key interventions: (i) registration of all births and deaths; (ii) targeted behaviour change of women, their husbands and mothers-in-law; (iii) strengthening health service delivery—focus on SBAs, focus on postnatal care of mother and baby; (iv) service management—mainly about ensuring supplies and logistics; and (v) research focussing on quality of care, and verbal autopsy
National Policy on Skilled Birth Attendant, 2006	
• *Women-friendly services* that are culturally sensitive and affordable to all families, especially those in poor and underserved areas	• Pregnancy and birthing care by an SBA, an accredited health professional such as a midwife, doctor or nurse • Focus on (i) production of SBAs by in-service training and incorporating SBA skills in pre-service curricula of ANM, SN and Doctor training; and (ii) deployment of SBAs to health facilities

- Availability of 24-hour emergency obstetric care

- Encouraged NGOs and communities to establish community based birthing units

- SBA to be supported by: strong referral back-up by a district health team, including supportive supervision; effective partnerships with other health workers, volunteers and TBAs, safety and security

National Safe Motherhood and Newborn Health Long Term Plan (2006-2017)

- *Equity and women centred care*

- *Equity in access and utilisation* of health services for newborn babies including safe motherhood services among the needy

- Access embracing financial, institutional and infra-structural factors including, but not limited to, funding, transportation and education; and *positive and welcoming service provider attitudes, trust, honesty, responsiveness, accountability*

- *Multi-sectoral approach* as underlying value to address Safe Motherhood and Maternal and Newborn Health (SMNH) issues; the role of other sectors is particularly important in enhancing access and promoting equity

- *Women understood not simply as individuals*, but as members of families and communities functioning within complex relationships and social

- Eight strategic outputs to ensure progress in the health of mother and babies:

(i) Equity and access: empowerment of individuals, groups and networks with the maternal and newborn care related BCC messages and promotion of birth preparedness and non-discriminatory interpersonal communication between providers and clients;

(ii) Delivery of quality maternal and newborn care: 24-hour availability of skilled staff with essential drugs and equipment, good community and inter-facility linkages and feedback systems;

(iii) Public private partnership;

(iv) Decentralisation: planning and supervising capacity of District Health Office;

(v) SBA training;

(vi) Information management: collection and use of data according to ethnicity, caste and wealth; and supplement quantitative with qualitative information;

(vii) Physical asset management and procurement; and

(viii) Finance such as safety nets for poor and socially excluded.

expectations

- Ensure the *right to health as a fundamental constitutional right* of every citizen in accordance with the provision of Nepal's interim constitution 2006

- *Financial incentives to improve health outcomes*, providing incentives to encourage women to come to health facility to have their babies as well as pregnancy check-ups

- The intention of the policy is clear on promoting facility based birth by allocating incentives to women to come to health facilities for pregnancy check-ups and birthing; to s*ervice providers* to motivate them provide birthing care at health facility; and to *health facilities* to encourage them strengthen birthing and emergency obstetric care

- Expanded the concept of birthing units by setting specific criteria such as separate birthing room, living apartment for SBA, equipment, 24-hour presence of a SBA including a support staff, good referral network, friendly behaviour to woman and her visitors, and the respect of a woman's privacy

- Obstetric reporting to the district and central department of newborn deaths, stillbirths and babies resuscitated for asphyxia management by each health facility

- Birth or the death registration of a baby, providers receive incentive of homebirths only if births or deaths are registered by parents

Maternal and Perinatal Death Surveillance and Response (MPDSR), Guideline 2014

- Value of a life of every mother and every baby; every death can provide information that can result in actions to prevent future maternal and perinatal deaths

- Self-reliant and sustainable approach to the improvement of health care for women and their babies

- Linking the information system with quality improvement process at a health facility level; real-time monitoring of deaths and assessment of interventions employed. Two main focuses are on:

(i) Notification of every death, and (ii) review for further actions to prevent future deaths

Community Based Integrated Management of Neonatal and Childhood Illness (Programme Management Module), 2015

• Reaching care to disadvantaged and marginalised groups	• Takes into it the lessons from CBNCP, and merges the package with IMCI--thus making a single package for managing newborn and all under-five year old children's health problems
• Provision of quality care through a single integrated package of interventions for newborn and under-five children	• Despite the *community-based* in its title, emphasis mainly on promotion of health facility based births and strengthening of quality of care from health facilities to prevent newborn deaths
• Community-based care	• Focus on strengthening the capacity of health facilities to manage and treat newborn babies' complications such as infection, asphyxia and low birth weight
	• Added a component which describes treatment of baby's cord infections by using an antiseptic ointment, chlorhexidine
	• Does not consider management of asphyxia as local health volunteers' job, which however was considered in previous version of the document—the Community Based Newborn Care Programme
	• Envisioned developing one to two birthing centres per district to ensure quality referral care for newborns with complications

Source: Based on review of policy related documents

The review of individual policies and the summary table (Table 5.1) highlights the following key aspects:

Target population

It is seen that over time there is a shift from a sole focus on maternal care to newborns but less on stillbirth. At the strategy level, Nepal developed a range of policies, plans and guidelines from around the millennium which started to increase the focus on infant and newborn survival. Prior to this date the policies' key focus was on maternal survival and although some policies mentioned aspects of perinatal survival and stillbirth, the strategic activities predominantly focussed on mothers. The inclusion of newborn care as a priority problem has occurred from 2004 onwards with Nepal's first ever National Neonatal Health Strategy. The focus of all policies remained on newborns except the MPDSR focussing on review of perinatal deaths including maternal deaths. This was limited mainly to identifying medical causes of perinatal deaths, and avoidable factors at the health facility level.

Evidence base

Nepal's policies have been up to date in terms of adopting best medical evidence internationally from WHO, UNICEF, USAID; and Nepal's national demographic and health surveys. Although it is acknowledged that the policies need to be tailored to local socio-cultural aspects, there is a clear lack of auditing of local socio-cultural contexts. Policies have acknowledged the need to address inequitable outcomes in newborn deaths. Yet, the policy interventions have been informed by medical evidence in reducing perinatal mortality and show little focus on understanding of the sociocultural or geographic context of the women and communities on whom they focus. Despite policies outlining home/community, health facilities and hospital as service delivery platforms, the focus remained mainly on changing health related behaviours and attendance at formal health facility based care.

A range of interventions along the continuum

These policies have presented a range of interventions across the continuum from conception to the early months of life—some with greater focus on pregnancy, and others at birthing and during the postnatal period. The key interventions during pregnancy comprised distribution of iron and anti-worm tablets, Tetanus Toxoid immunisation and introduction of antenatal check-ups during pregnancy. In the area of newborn care the main focus has been on immediate medical care of newborns after birth and during the postnatal period.

A move from community towards health facility

Policies have prioritised delivery of quality care during pregnancy, birthing and for newborn in health facilities, with quality defined primarily in terms of birthing in institution, births and postnatal care attended by SBAs. They have also focused greatly on identifying and reviewing the causes of

newborn deaths occurring at health facility level but not in the community/home where most of the mountain births take place. The large number of deaths occurring at home and in communities are still not subjects of such review. Lately, policies have explicitly discouraged homebirths. Policies have incentivised women to encourage them to come for antenatal check-ups and birth at health facilities. The policies also introduced birthing units and ensured they are provisioned with 24/7 availability of SBA at such health facilities. The provision of incentives to increase the numbers of women willing and able to travel to health facilities for pregnancy checks and childbirths is also strongly prioritised. FCHVs have been utilised to distribute iron and anti-worm tablets, to treat and refer newborns and to push women from communities to health facilities for antenatal and birthing care.

Overall, all policies have a consistent emphasis on improving access to health facilities. In this regard, the focus has been on system strengthening including: improvement in provision of birthing facilities such as birthing units; staff: SBAs as birth attendants; and consumers: providing incentives for women to attend health facilities for pregnancy checks and childbirth.

Consideration of social determinants, right based approach and equity

Policies also outlined broader strategies in the health system and addressed social health behaviours. They aim to increase inter-sectoral collaborations and link interventions such as nutrition and family planning by working closely with NGOs and international agencies, and different departments and sections within government. By setting strategies to mobilise FCHVs for counselling, behaviour change and supportive care during pregnancy, birthing and the postnatal period, policies have prioritised home and community interventions to address the lack of preparedness during birth, to prevent harmful practices during birth and newborn care, and to prevent hypothermia and common infections such as pneumonia and diarrhoea.

At the value level, one policy, Maternal and Newborn Health Long Term Plan, 2006 to 2017, has specifically acknowledged the inequities in newborn/infant mortalities in terms of geographical location and family income. For the first time, this plan explicitly stated that equity and social inclusion will be one of the cross cutting strategies in accessing pregnancy and newborn care. Otherwise, the policies have no specific focus on either identifying inequitable outcomes, or developing approaches to address these on the basis of ecological region. The exception is providing a slightly higher amount of travel incentive for women from the mountainous regions compared with their hill and plains area *(Terai)* counterparts, presumably because they have greater distances to travel to come to health facilities.

A few policies identified women-friendly care, respect and privacy in health facilities, equity focus, and focus on socially excluded and under-served regions. The policies have discouraged homebirths and have shifted their focus to strengthening and delivering quality care from health

facilities. They have opened an avenue for partnership with the private sector particularly in expanding birthing units by sharing the cost to hire local ANMs in health facilities with NGOs, and in mobilising technical and financial supports of INGOs in newborn health. Likewise, the policies have assured free maternity care and incentives to women also coming to teaching and community hospitals.

5.5 Conclusion

This chapter has identified chronological changes in policies and strategies to include newborn survival as a policy focus in Nepal. Even though the policies have evolved over time to incorporate new evidence and an appropriate shift of focus from maternal survival to maternal and newborn survival, they have still not taken account of the many religio-cultural dimensions of maternal survival, successful pregnancy outcomes and newborn survival. The main content focus has been institutionalised medical care and behaviour change strategies for the communities. The focus of the policies remained only in ensuring survival of babies at and after birth. Prevention of stillbirths still received very little attention. In terms of regional focus, there is no acknowledgement of variation in social contexts and there is very little specific focus on improving newborn outcomes in the remote mountain areas which record the highest neonatal death rates.

Against the background of this national policy context, the subsequent chapters report findings from field research in Nepal's mountainous district. They will illustrate how the policies play out in daily life in these areas, how women and their families losing their babies respond, and what health workers are experiencing in the field. By providing an understanding of lay experience, the subsequent chapters will illustrate the extent to which policies have been translated into practice and the existing gaps. The chapters will provide recommendations for improvement focussing on discussions about translation of policy strategies into implementation realities such as targeting ranges of interventions along various continua (e.g., pregnancy to postpartum, and home/community to health facility) in terms of what this would mean, if and in what ways such continua have worked to improve individuals' lives; and how the identified policy values have been reflected in providing health care to impact on perinatal survival in Nepal's remote mountain villages.

The subsequent chapters (Six, Seven and Eight) present and discuss key themes which emerged from the interviews. The next chapter discusses religio-cultural contexts of perinatal deaths in the study villages.

BELIEFS AND EXPERIENCES ABOUT PERINATAL SICKNESS AND DEATH: ACCEPTANCE AND FATALISM

The previous chapter presented a critical account on the policy context of perinatal survival in Nepal. Before the year 2000, national policies on maternal and child health had little focus on poor perinatal[12] survival. Although policies after the year 2000 placed more emphasis on preventing neonatal deaths, they did not explicitly emphasise the prevention of stillbirths. The national policies acknowledged key values such as equity; right-based approach; culturally appropriate care; access to women-friendly 24-hour childbirth services; social inclusion in maternal and newborn care; and counting every death (stillbirths and neonatal deaths). Despite the call for community-based interventions to tackle the problem of high perinatal death, policies primarily focussed on the introduction of basic medical care for the treatment of infectious diseases in newborns, promotion of health facility births, and the case review of perinatal deaths at district hospital and health centre levels. The policies initiated skilled birth attendant (SBAs) programmes, introduced birthing units to extend 24-hour birthing services in rural areas, encouraged births at health facilities by providing monitory incentives to women attending birthing centres, and identified comprehensive childbirth care for example provision of caesarean deliveries, blood supply and management of maternal and neonatal complications to be provided by district hospitals. The policies acknowledged the need to focus on rural and disadvantaged populations for perinatal survival. However, there is not yet a separate rural or subregional specific health policy to address perinatal health issues in the remote and mountainous regions of the country.

The present and subsequent two chapters present the key findings which emerged from this study. In the present chapter, the three key themes in relation to religious and cultural factors influencing perinatal death are presented and discussed. The themes which emerged are presented in a diagram below (Figure: 6.1).

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[12] Perinatal deaths: Unless otherwise defined, perinatal death refers to both the stillbirths and neonatal deaths (deaths occurring in the extended perinatal period of 22 weeks in pregnancy to up to a month after birth).

Figure 6.1 Fatalistic beliefs about, and acceptance of perinatal sickness and deaths

Source: Drawn by the author based on data analysis
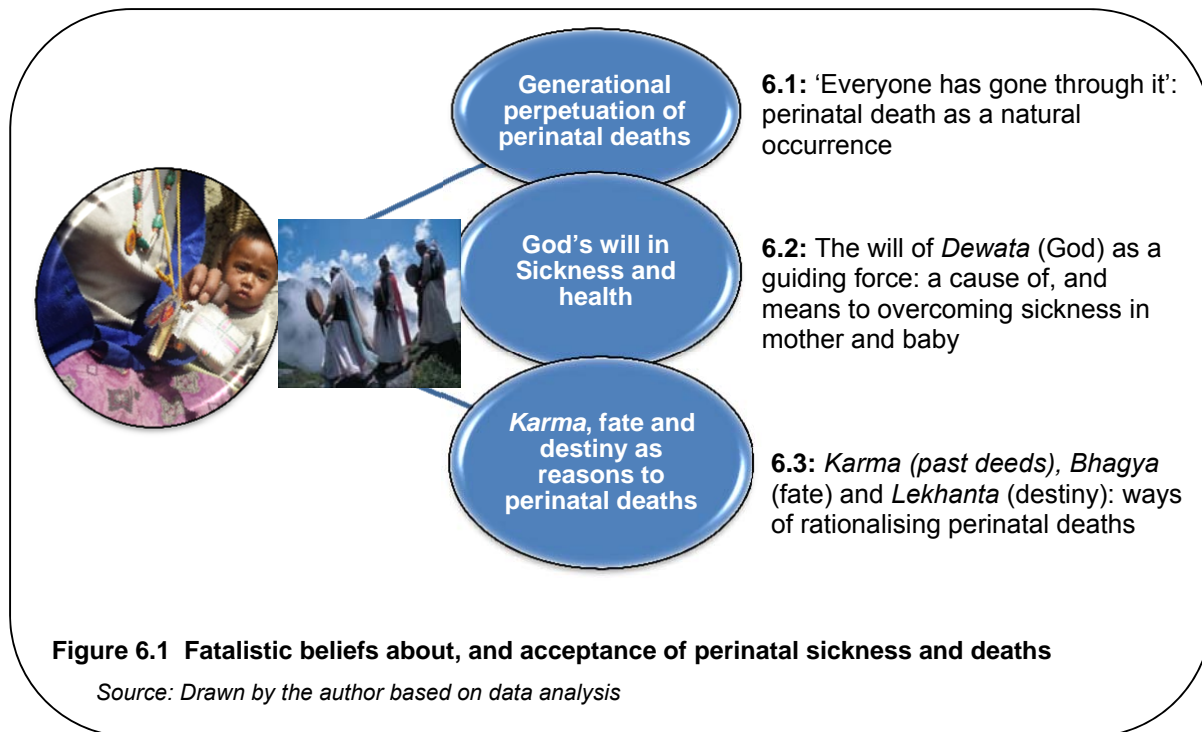
6.1 'Everyone Has Gone Through It': Perinatal Death as a Natural Occurrence

The majority of women from the study areas viewed perinatal death as a common and accepted occurrence. The similarity of the experience of perinatal deaths among women, their mothers, mothers-in-law, sisters and sisters-in-law, and neighbouring women in their communities has made perinatal death a common experience for everyone. This has led them to accept perinatal deaths as natural occurrences.

Perinatal death as a generational continuum

Interviews with the women show how perinatal deaths are perceived as common phenomena in every woman's reproductive life. For Bishnumaya,[13] perinatal loss was seen as a normal occurrence experienced by her parents and in-laws. These stories have hugely influenced Bishnumaya to normalise her own experience.

> *I heard my grandmother had 10 births (Sutkas—childbirths). All of her babies died. Then she was not pregnant for the next 12 years. No one thought she would have a baby again. But, after 12 years, she delivered my father and his three sisters. Therefore, my father tells me not to worry. My father says, ' you are young, you can bear babies, you haven't lost anything'. My father-in-law is also the only surviving son in his family. (Bishnumaya, a 20 year old mother)*

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[13] The names given in this thesis are not the real names of the participants. All of the original names have been changed for the sake of confidentiality and anonymity.

> **Bishnumaya** is 20, and studied up to grade four. She belongs to an upper caste. She is currently pregnant after the loss of all her previous three babies. She lost her first baby at seven months of pregnancy when she was 15. Both her second and third babies died on the day after birth. Her husband studied up to grade 10, and is currently working as a social mobiliser with a local communit-based organisation. **[Box 6.1]**

Another participant, Bishnumati talked about her own and her sister's experience of losing babies. Both the sisters have lost their babies, and it is evident from Bishnumati's story that the losses are perceived as a common phenomenon that everyone is going through.

> *My sister lost two babies, a boy, and a girl. We both lost our babies. Now she has two living children, and I have four. Everyone has gone through it. We can do nothing about it.*
> *(Bishnumati, a 31 year old mother)*

> **Bishnumati** is a 31 year old illiterate mother of four young children. She belongs to a lower caste. She lost babies during her first and second pregnancies, the first one on the 15th day after birth and the second in the eighth month of pregnancy. Now, Bishnumati has a surviving newborn girl aged 14 days. **[Box 6.2]**

Participants do not keep an account of the number of babies they have lost as such losses are seen as a reality occurring to everyone. They instead keep a count of babies that have survived. Perceiving perinatal deaths as inevitable, women do not even consider sharing stories about their losses and have simply ignored these losses and looked to the future, with the hope of bearing another child who would survive.

It may be worth noting that the continuing high toll of perinatal mortality has influenced the participants' perceptions about ongoing perinatal deaths, and such perceptions have not helped in any way to control the scourge of perinatal mortality in the villages. Far from being an outcry, one or two deaths in a family are perceived as natural occurrences and readily accepted. Despite two recent perinatal deaths in his own family, Birupa's father-in-law, a local leader, states that there are 'very few deaths' in the villages.

> *You know before, all the places on the bank of the stream over there [he points towards the stream] used to be babies' cemetery. You did not have enough space to bury them on the bank; no stones are left untouched by the deceased babies. You had to use the same burial space for others. You cannot imagine how many babies used to die. But, now there are very few deaths. We can get treatment for sick babies; they [health workers] provide immunisation [Tetanus Toxoid] in pregnancy. There used to be daily 3 to 4 neonatal deaths during second week of May (Zestha) to first week of July (Shrawan). I have seen this in my own lifetime. (Birupa's father-in-law, a 42 year old man, a local political leader)*

> **Birupa** is a 19 year old girl, married at the age of 15. She is currently studying in grade 12 together with her husband. She lost her first baby at seven months of pregnancy and her newborn died last

year on the 26th day after birth. Now, she has a boy aged 24 days as of the day of this interview. **Birupa's father-in-law** is a young, 42 year old local political leader in the village. **[Box 6.3]**

Other participants such as Devkumari's mother-in-law and Batuli's father-in-law also referred to the stream, which is locally known as the 'Stream of Death (*Madary Khola)'* (Plate 6.1). Participants named it so when there were many babies *(Jataks)* dying in the village, who were buried all along the bank of the stream.

Plate 6.1 The 'Stream of Death (*Madary Khola)'*, a name for a local place after a number of babies' deaths

Photo Credit: Author

Another young mother, Dilma lost two newborn babies. In accordance with the acceptance of the death of a newborn, usually in the first or second pregnancy as a natural occurrence, Dilma's mother-in-law assured her that the loss of newborn babies was not unusual and consoled Dilma by recalling her own story of perinatal losses.

> *I think some babies from the first few pregnancies die early; babies of later pregnancies survive. It is like this—some die and some survive. For me, six children died and six survived. It is also like this for my daughter-in-law (Dilma). She has lost two babies. (Dilma's mother-in-law, a 61 year old woman)*

Dilma is 21 years old. She is illiterate and was married at the age of 18. She lost two boys, one last year and another a year before. The first one died on the 10th day after birth, and the second on the15th day after birth. **Dilma's mother-in-law** is 61 years old. She lives with her husband, two sons and two daughters-in-law. **[Box 6.4].**

A notion of 'generational continuum' on perinatal death by families was confirmed by a local auxiliary nurse from the *Lama* community:

> *Village women believe that losing a baby is a generational continuum in their families. They say, 'my sister also lost one, my mother-in-law had the same experience and my mother had*

*also lost babies. Therefore, it happened to me too; now onwards the babies will survive'.
They usually call a Lama for prayer when they have lost a baby already [usually, after the
loss of the first child]. They call him (a Lama) to prevent babies' deaths in future*. *(Auxiliary
Nurse Midwife, HSP 5)*

Such a notion of 'generational continuum' has trivialised perinatal deaths in the villages and thus
perinatal death was considered as a common reality rather than a preventable occurrence.

Similar incidents of baby losses having been experienced by health providers and local female
volunteers further confirm the notion of perinatal death as a normal occurrence by local families.
Aspura, despite the loss of three babies, felt reassured about the natural occurrence of her losses
when she knew about the perinatal loss of her neighbouring female community health volunteer.

> *That female health volunteer [she points towards a nearby female community health
> volunteer's house] lost a son soon after birth. And, the two women over there lost their
> babies. It is like this here, occurs with everyone. (Aspura, a 26 year old mother)*

Aspura is a 26 year old woman, literate and married at the age of 15. She is a mother of three
young daughters. She lost three babies—two twin boys last year, one on the seventh day, and
another on the eighth day after birth and one newborn girl three years ago. **[Box 6.5]**

Timing and perinatal deaths: low level of concern about early lives

The timing of death is also important on how families perceive baby losses. There is an association
between the time of death and the level of acceptance, the sooner the baby dies, the more
acceptable it is for the parents and the community. For example, a perinatal death is commonly
accepted when it is a stillbirth. This acceptance is still high for a baby dying after birth while the
woman is confined in *Gotha (Gothabhitrai Mareko)*.

A stillborn baby *(Hudaimareko)* or the death of a newborn girl is of even less concern to women
and their families when they have surviving children. This is particularly a case when the baby is a
girl who is seen as a burden to families while they have to struggle to meet their basic needs. This
is evident in conversation with Hashakali when she stated that she became less worried about the
stillborn baby that occurred last year. She added that it (the stillbirth) made her able to begin work
sooner. She almost considered the loss as something that happened for a good reason.

> *I didn't feel worried about the stillbirth (Hudaimareko). I felt it was okay; it rather made me
> easier to resume my day to day work sooner. I have these young two girls and a boy. With
> that baby alive, I couldn't have gone anywhere to work, hard to manage even basic foods
> and clothes for these children. It is hard to survive without working. (Hashakali, a 25 year old
> mother)*

Hashakali is a 25 year old, lower caste, illiterate mother of three children—one son and two
daughters. She was married at 15 years of age and is currently pregnant for the ninth time.
Hashakali had three abortions and two foetal deaths at the fifth and eighth months of pregnancy.
Her husband is currently working in India as a labourer. **[Box 6.6]**

Similarly, Latima's husband described the perinatal losses of his wife, using the term *Aadanjhadne,* referring that it was a premature baby lost in pregnancy. In participants' local dialect, *Aadanjhadne (foetal death)* is used interchangeably with *Pakhala* (diarrhoea). To them, the word death or loss only refers to baby's death after birth.

> *We have two sons and a daughter. One newborn girl died two years ago on the sixth day. After this, my wife had an Aadanjhadne, but that was not a death, she lost it at six months of pregnancy. (Latima's Husband, a 42 year old father)*

Latima is a 32 year old illiterate woman who became pregnant ten times but lost seven of them including stillbirths, infant death and toddlers' deaths. She had stillbirths in two pregnancies, both in her final month *(Hunemahina)* of pregnancy, and one early neonatal death two years ago on the sixth day of birth. Her husband is 42 year old illiterate farmer. The couple live with their three children. **[Box 6.7]**

Death of a baby before the last month of pregnancy *(Hunemahina)* is not a concern. The concern about a baby's death increases after a few days when everyone in the family has seen the baby. Perinatal deaths lack any ritual significance, such as the ritual funeral, *Kaajkriya* (Hindu's 13 days mourning after death of an adult person), *Juthobarne* (avoiding eating salt and meat for at least 13 days after birth), *Barkhi* (the annual worship and offer in the remembrance of dead souls). Birth and death registration of these early lives are perceived meaningless to people of these villages.

Participants describe a foetal death (death of the foetus during pregnancy) as *Pakhala or Pakhalajane*, which in their local conversation means non-significant premature deaths. *Pakhala* or *Pakhalajane* is translated as diarrhoeal disease, which metaphorically means a rather common and natural occurrence in the context of these villages. According to this usage, a foetal death is not seen as a loss of a life, but an event as lightly as diarrhoea.[14] This perception about foetal death is shown in an interview with a female community health volunteer:

> *There are many women losing their babies in pregnancy (Pakhalajane) and neonatal deaths. You can see these in every single house. Are we going to record all such deaths? What is the point of sharing stories of these deaths by these women? Two years ago, even the Auxiliary Health Worker (Doctor)'s sister-in-law lost her baby. I know two women there who lost their babies in pregnancy (Pakhala). A woman in that house [she points to the house] had twin babies, but both died as newborns. (Female Community Health Volunteer, HSP10)*

For the first and second months after the birth of a baby, women and their families are uncertain about their babies' survival. This makes them less sensitive about the deaths occurring during this period. The mother's survival is of greater concern than the baby's death, with the survival of a baby seen as a chance happening.

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[14] Diarrhoea is taken lightly, often neglected as a common experience in the context of these villages. When something is referred to as diarrhoea it means of little importance and not worth considering seriously.

Another nurse, interviewed in this research confirmed that women and families become concerned only if the baby dies after surviving the first two months.

> *I have heard from many people here. They say, 'no problem, she will have another baby next year'. Anyway, don't worry about it. This is not a grown up baby, better that it died early after birth. It is not a big thing, it was a very young baby, we didn't carry for longer'. If a baby dies at one month or at two months after birth, they don't worry much. It makes a difference if it was a grown up baby who they carried longer. (Senior Auxiliary Nurse Midwife, HCM3)*

The participants remember and feel sad about the deaths of their late infants and children who died after becoming able to crawl and walk around the house. Figure 6.2 illustrates how participants show their sense of concern (according to time of death) about perinatal deaths.

Figure 6.2 Acceptance of deaths, higher during early lives (in the perinatal period) and lower when baby starts crawling and walking

Source: Drawn by the author based on data analysis
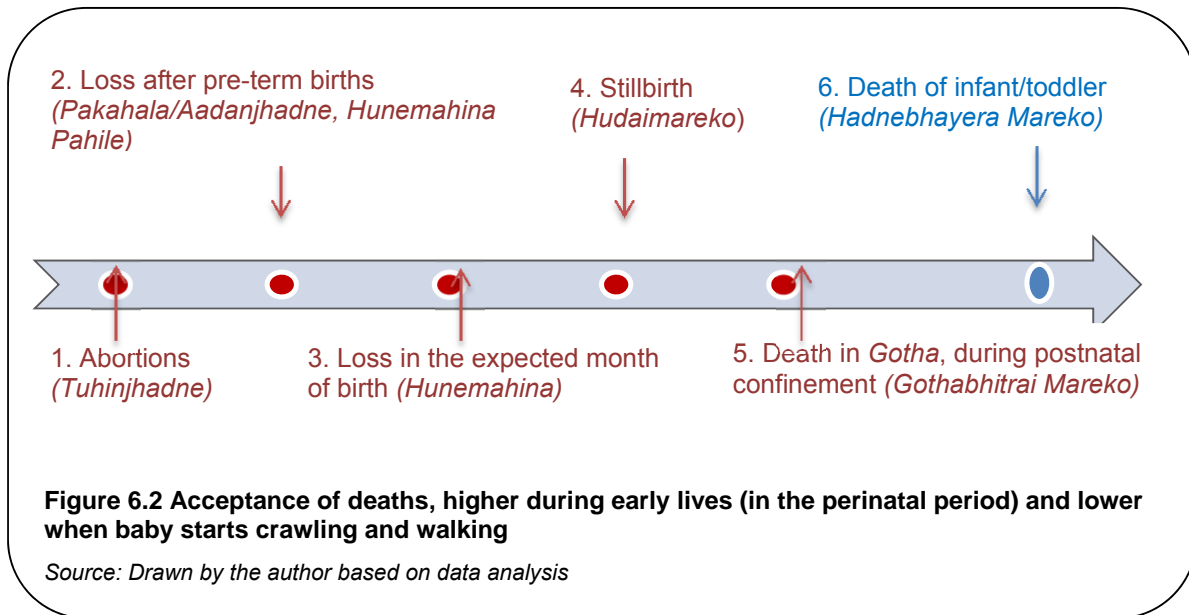
Perinatal deaths as not worthy to report

The quotes above clearly demonstrate the low attention given to perinatal death, not even worth registering or reporting by health providers. When the participant recruitment process commenced, the lack of death records were noted by me. Female community health volunteers could not remember deaths in their neighbourhood. Over time, during repeated contacts and conversations, they started recalling women who had experienced perinatal losses.

It is revealed from the conversations that these deaths in early life before mothers re-enter the main house from the *Gotha* (cowshed) after birth, are considered less important. Women stay in *Gotha* during birth and the postnatal period, usually up to three weeks and such deaths are considered of low significance and remain unrecorded, thus making these deaths invisible in the communities. In addition, as already stated, the women and families' feelings of uncertainty about their babies' survival has made them reluctant for registration and recording of births and deaths.

The poor reporting system is also a consequence of health system malfunctioning that will be further discussed in Chapter Eight.

To summarise, this section describes the acceptance of perinatal deaths in the villages. Perinatal deaths are a collective experience of everyone and they are considered as natural occurrences in people's day to day lives. Perinatal deaths were perceived as a generational perpetuation, and as of low concern and low social significance such as that accorded to diarrhoeal diseases *(Pakahala, Aadanjhadne),* and therefore, any news of perinatal deaths is not considered worthy talking about and reporting. This section has also shown that the time of death is an important factor in the fatalistic views on perinatal death. Stillbirths attracted least attention and concern compared with deaths after birth and the confinement period, and loss of babies in first or second pregnancy are factors which affect participants' perceptions related to acceptance.

The next section describes *Dewata* (God*)* as a guiding force, influencing perceptions around mother's and baby's health and sickness.

6.2 The Will of *Dewata* (God) in Health and Sickness: A Cause of, and a Means to Overcome Sickness in Mothers and Babies

The previous section described women and families' perceptions of perinatal deaths as natural occurrences experienced by everybody in life. The following section discusses the participants' belief that the will of *Dewata* (God) causes sickness and finds a cure for it if it is meant to be.

The word *'Dewata'* is a collective name for Hindu Gods and Goddesses. The belief that God's will is the cause of health and sickness is an age-old view universally held by women and their families. This belief is commonly shared, and has been culturally embedded in both the Buddhist *(Lama)* and the Hindu *(Khasan: the Aryan)* communities in the study villages. One can find God represented in various symbolic forms, everywhere: in the farmland, on the banks of streams (Plate 6.2), on street corners, in the forest, inside the house and in the middle of the villages across both the *Khasan* and the *Lama* communities.

Plate 6.2 *Dewata* (God) in the villages as symbols 'holy ribbons and stone' on a local riverside, and a symbolic temple in a paddy field; Photo Credit: Author

6.2.1 *Dewata* (God) and Childbirth Complications: Seeking Faith Healers during Pregnancy and Childbirth

God's will is believed to be a key cause of pregnancy and childbirth problems. Women believe that God influences the labour and birth outcomes. Kunjong believed that her breech presentation (the baby's legs appeared first) during birth and the neonatal death was due to not worshipping their God (due to not doing *Gyana*). She had labour pains for two days with a breech presentation of the baby and the baby died shortly after birth.

> *My baby did not die due to breech presentation (Ulto). It is because God (Dewata) was angry with us [she cries]. My family should have called the faith healer (Lama), and prayed to God (Gyana). They didn't do anything to please God at home [she cried], therefore my baby died. Local faith healer had told that it was not going to be a good fortune if we didn't worship God. I had also seen a dream, it was not a good dream [cry continues]: I dreamt that I had been to a faith healer (Dhami) and he laughed at me and spoke 'you have to worship God'. (Kunjong, a 22 year old mother)*

Kunjong is 22 years old. She is an illiterate woman from the *Lama* community. She was married at 20. It is less than two years since Kunjong lost her baby on the day after birth. It was her only pregnancy. Her husband is an illiterate, 18 year old shepherd. **[Box 6.8]**

Critical role of faith healers

Faith healing has been a key source of reinforcing participants' belief in God as a guiding force in health and sickness. Local faith healers are considered as the best persons to contact first although they do not even touch a woman during birth. They are called to be present during birth and are relied upon to relieve a woman from pain and suffering, to speed-up the birthing process and to save the lives of mothers and babies. They are also relied upon to help with other family

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health issues and pregnancy complications such as faints during pregnancy; prolonged and severe labour pain; breech position of the baby; and when a woman feels weak during the birthing process. When Hitchma's pain was more than bearable, her family invited a local faith healer to ease and expedite her labour. I noted that Hitchma did not even think of going to a health facility, as seeking assistance from the faith healer came naturally to her.

> *We invited the faith healer (Dhami). He did Mantra on my abdomen and told me that I will give birth sooner. I had severe pain in the morning [at about 5:00 am], and delivered the baby by 11:00 am. (Hitchma, a 24 year old mother)*

> **Hitchma** is a 24 year old woman, illiterate and from the *Lama* community. She lost a newborn baby two years ago on the 15th day after birth. Her husband is a student, currently studying at grade 11. **[Box 6.9]**

Faith healing is an old generational tradition and has a strong foothold in the villages. It is believed that devoted faith healers can pass their wisdom *(Dhami Viddhya)* to new members both within and outside their family, and produce new faith healers, both men and women. The faith healers outnumber health volunteers and health service providers. There are different cadres of faith healers locally known as *Dhami-Jhakri, Dangri* in the *Khasan* community; and *Lama, Chumba* in the *Lama* community. However, people in both communities commonly refer to them as *Dhami-Jhakri.* There are other groups of local herbalists called '*Baijis*' who are essentially meant to treat ailments with local herbs. *Dhami-Jhakris* also prepare herbal medicines, and *Baijis* also do the work of *Dhami-Jhakri*.

The faith healers consider their healing practice as a duty (*Dharma*) of obeying their God. The care from the faith healers is affordable as they demand a few rice grains to recite Mantras, or they do it for a small gift, sometimes merely a packet of cigarettes. Faith healing practices are intermingled in both *Khasan* and *Lama* people. Women and their families believe faith healers are those chosen by God, who can understand God's language and can alleviate sufferings of any kind including their sickness.

God's will and impact in health care seeking

Seeking assistance from professional health providers comes last when faith healers fail to provide help. Women either do not go to health facilities, or go there only at a late stage, which results in the death of mothers and/or their babies. A local Auxiliary Nurse Midwife reaffirmed:

> *She [referring to a pregnant woman] was seven months pregnant. I asked her family to describe to me what had happened. They said that she died due to God's curse (Dewatalagne). They added that her legs and feet were swollen (Goda Osayeko), she had a headache, and couldn't see properly. (Auxiliary Nurse Midwife, HSP8)*

Health workers are sought only at a very late stage when labour is prolonged, usually after the faith healers fail to provide help. As stated in the above quote, this occurs mostly when women and

families are given permission by local faith healers to contact the health providers. Even though at a late stage, they do not stop continuing to take care from their faith healers, and they do so even after contacting the health providers. A local health worker from the second village described his experience when he had to attend a woman in labour at home together with a faith healer:

> *The faith healer (Lama) was ringing a bell around and reciting prayers (Mantras). I had to deliver her by rupturing her membrane. They invite us only when they are permitted to do so by the faith healers. (Auxiliary Health Worker, HSP7)*

6.2.2 *Dewata* (God) After Birth—Seeking and Receiving Care for Babies

Women and families attribute their babies' sickness to God's displeasure. In their daily conversation, different types of sickness are together called 'God's wrath (*Dewatalagne)'.* It is believed that sickness occurs when God is not pleased. To alleviate the sicknesses, one is expected to please God by prayers, wearing amulets, sacrifice (animal) and offerings made through faith healers.

Local sickness labels

The different sickness types frequently described by the participants are listed in Table 6.1.

Table 6.1 Sickness types reported by women and families in the villages

Sickness types	Beliefs
Type 1 sickness: God as a cause and means to alleviate/cure sickness	
- Influence of the forest God (Lasolja/ Ban Dewata); - Influence of the God of the parent's home *(Maiti Dewata)*, God of in-law's home *(Poili Dewata)*, and God of a family clan *(Kul Dewata)*; - Astrological hindrance *(Grahalagne);* - Influence of a ghost *(Bhut/Lago/Masanlagne);* - Witchcraft, evil eye *(Boksolagne/Koptini);* - Influence of the dead spirits of family or close relatives *(Muiyalagne);* - Influence of the snake God *(Naglagne);*	God is a major cause of sickness, and pleasing God is believed to be the key solution to alleviate sickness. Faith healers are sought for prayers, Mantra recitations, offerings (animal sacrifices and others), provision of amulets etc.
Type 2 sickness: God as a cause, with alleviation/cure through God and local traditional therapy	
- Continued baby loss related to weakness of womb *(Mojhlagne);* - Effects of heat with symptoms of diarrhoea and fever *(Taaplagne);* - Cough and cold *(Sardilagne);* - Pseudo teeth in baby's neck *(Chordat); and* - Sudden rainbow attack and death *(Banlagne).*	God is attributed as a cause, yet care is combined with local herbs. Faith healers who practise both faith healing and herbal practices are sought. These are characteristics of infections (diarrhoea, pneumonia, tetanus in babies) and anaemia and malnutrition in women.

Source: Based on data analysis; fieldwork, 2015

Type 1 sickness: God as a cause and a means to alleviate/cure sickness

The type 1 sickness labels as stated in Table 6.1 were attributed mainly to God's will. Participants believed to overcome these sicknesses by pleasing their God. Faith healers were utilised to make offerings to God and to make their God happy.

Boksolagne/Koptini (witch/evil eye) was a common belief when a mother could not secrete breastmilk until three days after birth. Tengri's family introduced pre-lacteal feeds, honey and a local alcoholic beverage *(Chhyang)* to the newborn, and also invited faith healers to help Tengri in secreting breastmilk. Tengri's mother-in-law stated:

For three days, there was no milk secreted from her breasts. We contacted faith healers (Dhami, Dangri) to avoid witchcraft...; four faith healers (two Dhamis and two Dangris) came to our home. After this, she had her breastmilk secreted. But, she was sick too and could not breastfeed the baby. We fed honey and Chhyang [a type of locally fermented beverage] to our grandson. We could not save him longer; he died on 27th day. (Tengri's mother-in-law, a 67 year old woman)

Tengri is an 18 year old, illiterate girl from the *Lama* community. Her husband is younger than her, aged 17 and an illiterate shepherd boy. Tengri married last year, and had a baby this year. Her newborn died on the 27th day after birth. **[Box 6.10]**

Likewise, Hitchma (Box 6.9) invited a faith healer after her newborn started continuous vomiting from the fifth day after birth. Her baby was believed to be inflicted by a ghost *(Bhut)* and the forest God *(Ban Dewata)*. She lost her newborn baby last year. She could not organise prayers for the forest God as suggested by a local faith healer *(Lama)*.

We contacted local faith healers (Dhami and Lama). They said the baby was under the influence of a ghost (Bhut). They also told me to pray to the forest God (Ban Dewata). But, the baby died early. I couldn't even manage to pray to the forest God. (Hitchma, a 24 year old mother)

In addition, participants believed that pregnant or postnatal mothers become unwell if they attract the wrath of God while on the way to, or working in the forest for grazing cattle and collecting fodder, firewood and grass. They believed that the forest God could affect a baby in the womb. Although Gobnajong had a fall in the forest during the last month of her pregnancy, she did not believe that it was the fall that harmed the baby in the womb. Rather she believed it was the influence of the forest God.

I didn't go to the local health worker (doctor). I didn't go to the health post. I went to worship the forest God (Ban Dewata). I didn't know anything. I could feel the baby moving [in the womb], and thought that it was okay [but at the time of birth, the baby was dead]. (Gobnajong, a 34 year old mother)

Gobnajong is a 34 year old illiterate woman, a mother of three daughters from the *Lama* community. She lost two babies, one at the eighth and another at the last month of pregnancy. Her husband, 37 years old, is a local carpenter. **[Box 6.11]**

In the *Lama* community, the forest God is known by the name *Lasolja.* The forest God is also believed to inflict a baby with severe cough and cold and thus they worship the forest God to heal a baby with severe pneumonia. As a part of invoking and pleasing the forest God, they go with a bunch of green grass to the forest, and return home. During this time, they remain silent and do not speak a single word with anyone. They put the grass on the baby's head and pray to the forest God to cure the baby's sickness.

The God of a family clan *(Kul Dewata)* and astrological hindrance *(Graha)*, which is the influence of heavenly bodies, is also believed to inflict sickness on mothers and their babies. In addition to the

family God (*Kul Dewata*), the participants to this research also referred to the God of the parents' home *(Maiti Dewata)*, and God of in-laws' home *(Poili Dewata)*.

After a series of perinatal deaths, Bishnumaya (Box 6.1) described how her family worked to make their Gods happy to ensure her babies survived:

> *We worshipped to overcome astrological hindrance (Graha), contacted faith healers (Dhami) from around the villages to know why I continued losing my babies. We worshipped the God of my parents' home (Maiti Dewata) as well as the God of my in-laws' home (Poili Dewata). We tried our best to worship and pray to God. I don't know why I continue to lose my babies. (Bishnumaya, a 20 year old mother)*

To prevent the loss of the baby from her current pregnancy, Bishumaya's family invited a local faith healer and worshipped God to avoid the husband's astrological hindrance *(Graha)*. She said the family spent about 75 AUD (6,000 Rupees) to worship God. This is a large amount in the context of these villages. In the *Khasan* community, if a woman gives birth at her parent's home, the God of the parent's home is believed to affect both the mother and baby. People sacrifice hens, goats, sheep or offer cash and other offerings in kind to please the God and to prevent any unforeseen harm to mother and baby. Shivakumari described:

> *There is God (Dewata) in my parents' home. If I had delivered there, we had to offer hens, goats and many other things to favour the God there. It is very expensive. But, if I deliver here [in her in-law's house], we don't need to offer anything. (Shivakumari, an 18 year old mother)*

Shivakumari is an 18 year old girl, belongs to the upper caste, studied up to grade eight and got married at 15. She lost a newborn baby two years ago on the seventh day after birth while in *Gotha*. Her husband is a student, currently in grade 10. **[Box 6.12]**

During her last month of pregnancy, Shivakumari was in her parent's home. Due to the fear of God in that home, Shivakumari returned to her in-laws' home walking three hours after the commencement of labour pains. Shivakumari gave birth to a live-born baby, but the baby died during her confinement in *Gotha*.

Women believe that the unhappy God of family clan (*Kul Dewata*) could bring disgrace to the land and the site of their house. Kanghmu, who lost her two newborn babies, believes that these deaths could be attributed to the God of her in-laws' home. She frequently contacted a local faith healer to please the God. Kanghmu also consulted the faith healer when her newborn baby was bleeding from the umbilicus. However, her baby died on the 11th day after birth.

> *Both the faith healers (Dhami and Lama) were right about me; there is something wrong with this house [the site of the house]. I lost my two children here. They said, 'the God (Dewata) of this house is unfavourable to you'. Like they said, both my children died at this house. (Kanghmu, a 25 year old mother)*

Kanghmu is a 25 year old woman, illiterate, upper caste and from the *Lama* community. She was married at 16, and is currently pregnant with her fourth child. She lost one newborn and an infant. **[Box 6.13]**

Kanghmu also attached a poster to the entrance of her house (Plate 6.3) to ward off any bad influence of an unhappy God and to prevent the death of her baby from her current pregnancy.
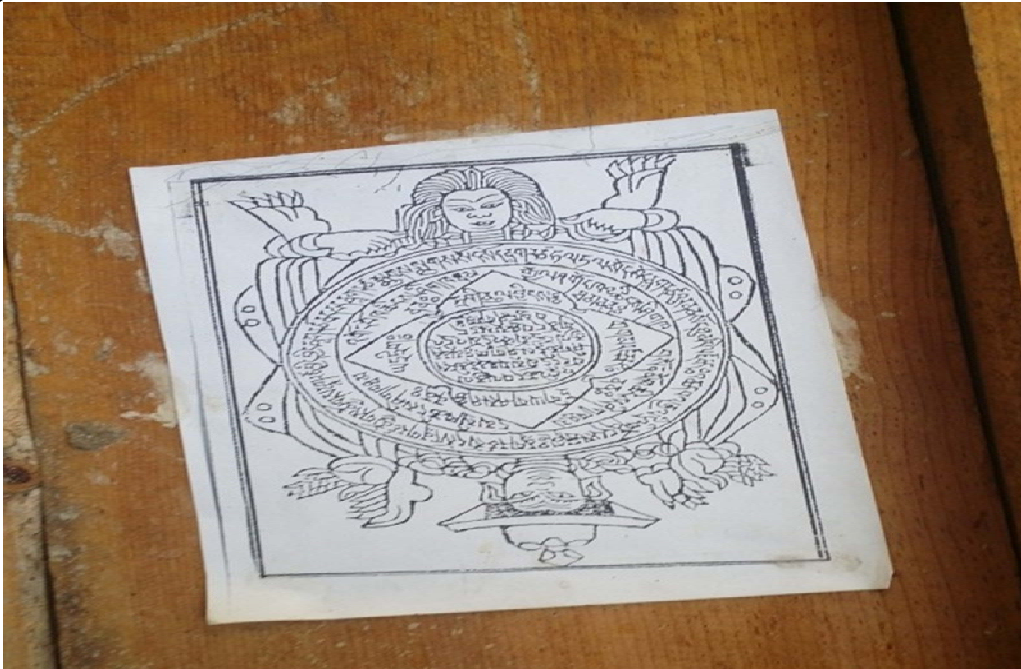
Plate 6.3 Posters to ward off the ghost *(Bhut/Lagobhago)* **that is believed to cause sickness and deaths of babies;** Photo Credit: Author

They also believe that an angry God can inflict harm through hungry dead spirits (Muiya) of the deceased family members or close relatives. Tengri's (Box 6.10) mother-in-law believed that the deaths of her grandchildren (two newborn babies) were due to hungry dead spirits (Muiya).

> My mother-in-law is a hungry dead spirit (Muiya); her grandmother in her maternal house is the same (Muiya). Therefore, it was not a sign of something good (Niko) occurring in our families. We contacted faith healers (Dhami, Dangri) to offer the spirit; we invited four faith healers together. Yet, the baby didn't survive. Nothing worked. (Tengri's mother-in-law, a 67 year old woman)

From the viewpoint of most participants, providing offerings to please God is the only way to overcome sickness, and to prevent future deaths. Yanghmu wondered whether God was still unhappy and seeking more offerings from her when she lost her two babies.

> Both times, I felt babies were alive and moving in my womb. But, when delivered, both were dead (stillborn). I don't know why. You know, for the first time, I think it is due to God, we have God inside our house (God's statue). Maybe, God is seeking lamb, oil or something more, I feel like God is not happy. (Yanghmu, a 28 year old mother)

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Yanghmu is a 28 year old girl, illiterate, upper caste and from the *Lama* community. Yanghmu lost two babies in the last four years, both in her last month of pregnancy. **[Box 6.14]**

Seeking health care makes God unhappy

Since health and sickness are strongly linked to God's will and happiness, seeking care from health facilities is a low preference, very low amongst the *Lama* families. For an unhappy God, the medicine from a health facility is perceived to have no effect. The participants are reluctant to contact health workers, and believe that seeking care from a health facility would even be harmful. Kunjong's husband (Box 6.8) described this situation:

> *In your community (in the Khasn community), you go to the health post and get medicines, even if it is due to God's wrath (Dewatalagne). But, here in our tradition, if it is due to God, medicine doesn't work at all. If it was due to God, and they took medicine, it would further harm. (Kunjong's husband, an 18 year old father)*

Type 2 sickness: God as a cause, with alleviation/cure through God and local traditional therapy

The type 2 sickness labels as stated in Table 6.1 includes those sicknesses in which women and families attributed sickness to their God, yet they sought combined care including herbs from local herbalists, worship, prayers and Mantra recitations from the faith healers. They seek local herbalists, called *Baiji* to overcome sickness, particularly when the sickness types are perceived to be *Taplagne (effect of heat), Banlagne (rainbow attack)* or *Mojhlagne (weakness of the womb).* Even if it is the herbal medicine from *Baiji* (herbalist), they still focus on pleasing God through sacrificing animals and offerings. A baby is perceived to suffer from *Taplagne* when found hot (feverish), and having diarrhoea or vomiting. Devkumari (Box 6.15) believed that *Taplagne* (effect of heat) could be treated by making offerings to God. If untreated, it could result in sickness and deaths of babies. She explained:

> *They die very young. They die due to Taplagne (effect of heat). It makes their body hot and febrile, causes diarrhoea (Chherne), vomiting (Ukhalne), and Pneumonia (Sardi). Pastes made from herbs are applied on the baby's head and body. The babies also suffer from pneumonia and can die from it. For young babies, we also recite Mantras for Pneumonia. A faith healer, who practices both as a faith healer and a herbalist (Baiji) treats baby with local herbs, throws holy grains (rice) and water over the sick baby's body, and prays and worships God to heal the baby. (Devkumari, a 27 year old mother)*

Devkumari is a 27 year old, upper caste and illiterate *Khasan* woman, and married at 19. She has two girls and a baby boy, lost two newborn babies. Her husband who is an educated person, works as an assistant officer in a local government office. **[Box 6.15]**

Likewise, *Banlagne* (rainbow attack) is perceived to attack older people as well as newborns, usually leading to sudden sickness and death. Participants locally described *Banlagne* as *Chhitopadne* (lightning attack)*.* They labelled a sickness as *Banlagne* when it had a sudden effect, sometimes speech impairment, high fever, paralysis, or sudden deaths. A sickness was also

attributed as *Banlagne* when they did not have any other explanations for babies' deaths, such as deaths soon after birth. They described two kinds of *Banlagne* (rainbow attack): *Pursoban* (Sharp type) and *Mahuban* (Dull type). The former is believed to be fatal and believed to cause sudden death of a young baby, particularly newborns; and the latter is believed to make a baby sick and live with permanent disabilities. Rupamati added that *Banlagne*, particularly the *Mahuban* (Dull type) could be treated by an experienced herbalist and faith healer together. Both Rupamati and her husband believed that it was the *Pursoban* (Sharp type) that led to the death of their newborn when their baby died suddenly without noticeable sickness.

> *Babies immediately die when it is Pursoban. These babies usually ooze blood in their mouth or nose. Pursoban usually hurts above the neck. My son had blood in his nose. (Rupamati's husband, a 22 year old father)*

Rupamati is a 20 year old girl, illiterate, and from a lower caste, married at 12. She is currently pregnant for the third time. She lost a newborn three years ago on the 20th day after birth. Her husband is a daily labourer. **[Box 6.16]**

It is believed that as a cure for *Banlagne* (rainbow attack), people need to offer a knife and a bird feather while worshipping their God. Rupamati described:

> *The Pursoban (Sharp type attack) usually hurts young babies. Mahuban (Dull type attack) doesn't usually kill the baby immediately, it sickens them. We understood this only recently. We didn't know this before. Daughter-in-law of my neighbour also lost her baby boy due to Banlagne (rainbow attack). The baby vomited blood and died, it was Pursoban. Pursoban usually hurts the baby. It is very quick. Experienced herbalist can treat it. We need a broom, Khukuri (a knife) and a bird feather (Garud) to worship God to alleviate Banlagne. Rupamati, a 20 year old mother)*

Mojh or *Mojhlagne* (weakness of womb) is locally considered a disease of a woman's womb in which a woman is perceived to be unable to carry babies. She is believed to be more vulnerable to continuous baby loss in pregnancies or soon after birth. The participants believed that this occurs due to God's curse. The treatment for *Mojh* is believed to transfer this sickness to specific plants or fruit trees with the help of an experienced faith healer and herbalist. After transferring it to trees, the woman is considered to be free from *Mojh*. Latima's (Box 6.7) continuous loss of babies led her husband and neighbours to believe that she was suffering from *Mojh*. To transfer Latima's *Mojh*, her husband invited a local herbalist who was also a faith healer. Latima's husband described the process:

> *…he (Baiji) asked me for a hair clip (Dori), a pair of bracelets (Chuda), a mirror (Aaina), pink holy powder (Sindur) and a pair of clothes. He prayed and worshipped Dewata and transferred her Mojh to a plant in the local river. Then, she delivered a baby; the baby could not survive, it became weak and very thin (Chamdiyo). (Latima's husband, a 39 year old father)*

Like Latima, Bishnumaya's father-in-law also doubts whether it is a *Mojh* in Bishnumaya as she had continuous baby losses.

I don't know whether it is her fate (Bhagya), or her womb is not good (Mojh). People here also call it a Mojh. When a woman is not able to save her baby in repeated pregnancies, or when she gives birth before the term, or when she delivers a dead baby. My daughter-in-law might have Mojh. (Bishnumaya's father-in-law, a 55 year old man)

Perinatal losses: repeated pregnancies and aversions to family planning—God's will?

One way of reducing stillbirths and perinatal deaths is to plan the pregnancies appropriately by using family planning. It has been noted in the previous discussions that women suffering perinatal losses and stillbirths also go through many pregnancies. In the remote mountainous region of Nepal, particularly if the women are poor, malnourished and less educated, repeated pregnancies at short intervals are liable to terminate in stillbirths or neonatal deaths. Repeated pregnancies and the loss of babies are perceived to be heavily influenced by the will of God. There is a strong belief among women and their families that the use of contraceptives particularly vasectomy is against God's will. Despite having two or more children, men express no interest in vasectomy.

The Government's family planning programme establishes annual or even more frequent 'mobile vasectomy camps', and provides incentives to motivate men to have a vasectomy (DoHS, 2014) . Yet, there is a great deal of hesitancy about vasectomy in the local community due to a belief that it is against the will of their God. Additionally, vasectomy is believed to negatively impact on men's strength to do day to day work. This belief is particularly strong among the faith healers and many other families who have a physical statue *(Thaan)* of their God inside their house.

Participants believe that vasectomy makes their God unhappy leading to bad luck to their family such as disease or death of family members including the loss of babies in pregnancy, and deaths of newborn babies or damage to their livestock and property. This is cited by Kushumkali's husband as:

I am scared. No one has done it. If you do it before you have God (Chosen to invoke Dewata), that might be okay. After God comes into you, it is not good. It can go wrong. You might encounter any bad consequences of it. I am afraid if I become further sick. (Kushumkali's husband, a 33 year old father)

Kushumkali is a 31 year old woman, illiterate and from a lower caste, *Khasan*. She had had two abortions, two newborn deaths, and death of an under-five child. She lives with her husband and four children (one boy and three girls). Her husband is literate, a local labourer and a faith healer (*Dhami*) in the village. **[Box 6.17]**

For this reason, many women such as Kushumkali have preferred to use contraceptive methods themselves. Having had the same belief that vasectomy was against God's will, she did not want her husband to have one. Instead, she decided to use contraceptives herself by having female hormonal injections (known in local language as *Suhi*, which literally means needle).

No, he can't do that. He is a faith healer (Dhami). God (Dewata) comes into him [he has chosen to invoke God]. Therefore, he shouldn't do that. I have to use this hormonal injection (Suhi) even if I die. (Kushumkali, a 31year old mother)

In addition to the faith healers, the fear about vasectomy is commonly seen among other families. Although Dhanasila's husband is not a faith healer, Dhanasila does not want him to have the operation. Now, she uses an injectable female hormonal contraceptive from a private pharmacy.

I don't know what happens [laugh]. That is a tradition here, we shouldn't do that. God (Dewata) will be angry and will bring bad luck to our family. I started using Depo from a drug store. (Dhanasila, a 39 year old mother)

Dhanasila is a 39 year old illiterate lower caste woman married at 18. She lost a baby at seven months of pregnancy last year. She lives with her four children. Her husband, a local contractor, has been living with his second wife. He meets Dhanasila only occasionally. **[Box 6.18]**

Likewise, although Latima's husband, Birkhe (Box 6.7) is not a faith healer, he is afraid of having a vasectomy believing that his family God (*Kul Dewata*) does not favour it. Birkhe believed that his father's death at a young age was due to the wrath of God because his father had undergone vasectomy.

...because of our family God (Kul Dewata), the operation (vasectomy) won't suit me. My father had the operation, then this didn't work, he died when he was just 42, very young. He was very young. (Latima's Husband, a 39 year old father)

Although many participants appeared to find contraception other than vasectomy, acceptable, the motivation to have a live baby, preferably a baby boy [see Chapter Seven] prevents them from using any contraceptives. In addition, as described above, they are devoid of access to a range of contraceptive choices due to lack of client friendly counselling services in health facilities. During the fieldwork for this study, I did not find a single client being counselled for family planning, neither did I find a single packet of condoms available in the 'Condom Boxes' although the boxes were hanging on the walls of each health facility building. These boxes were just empty with cobwebs around them, and no health worker was found to pay attention to this.

In summary, this section examined the influence of God across the continuum from shaping contraceptive behaviour, care seeking during pregnancy, birth, and after birth for both the mother and babies. Belief in God emerged as a factor in health and sickness, a powerful agent influencing sickness and deaths of babies in the villages. Health problems of mother and babies including complications during pregnancy and birth are attributed to a range of different Gods. Sickness is believed to occur due to the disobedience of God and thus pleasing God has been seen as a way to cure sickness. This is mainly undertaken through seeking care from faith healers and local herbalists. This has been reinforced further by failures on part of the local health system which will be discussed further in Chapter Eight.

The next theme describes participants' rationalisation of perinatal deaths as *Karma* (past deeds), fate *(Bhagya)*, and destiny *(Lekhanta)*.

6.3 *Karma (past deeds)*, *Bhagya* (fate) or *Lekhanta* (destiny): Ways of Rationalising Perinatal Deaths

This theme describes how participants justified perinatal deaths relating them to their *Karma* (past deeds), fate and destiny.

The Oxford dictionary defines the Hindu or Buddhist notion of *Karma* as "the sum of a person's actions in this [life] and previous states of existence, viewed as deciding their fate in future existences" (Stevenson, 2010, p. 957). The Indian scholar, Krishan (1997) described *Karma* in the Hindu religious sense as an 'action potential' manifesting into a result or consequence which influences an individual during his/her next life. The nearest English translation of the word *Bhagya* refers to fate. In participants' day to day conversations, fate is often used interchangeably with *Karma*. Similarly, the English translation of *Lekhanta* means destiny, 'already written' or 'pre-destined'. *Lekhanta* is used differently from *Karma* and fate. A perinatal death is rationalised as *Lekhanta* (destiny) when it is destined to be a baby's personal future rather than to *Karma* or fate of a woman. Therefore, in rationalising their baby's death, the perceived fatalism becomes stronger from *Karma* (past deeds) to *Lekhanta* (destiny) (Figure 6.3).

Figure 6.3 Perception of the extent of fatalism increasing (from bottom to top, with the size of the circle)

Source: Drawn by the author based on data analysis
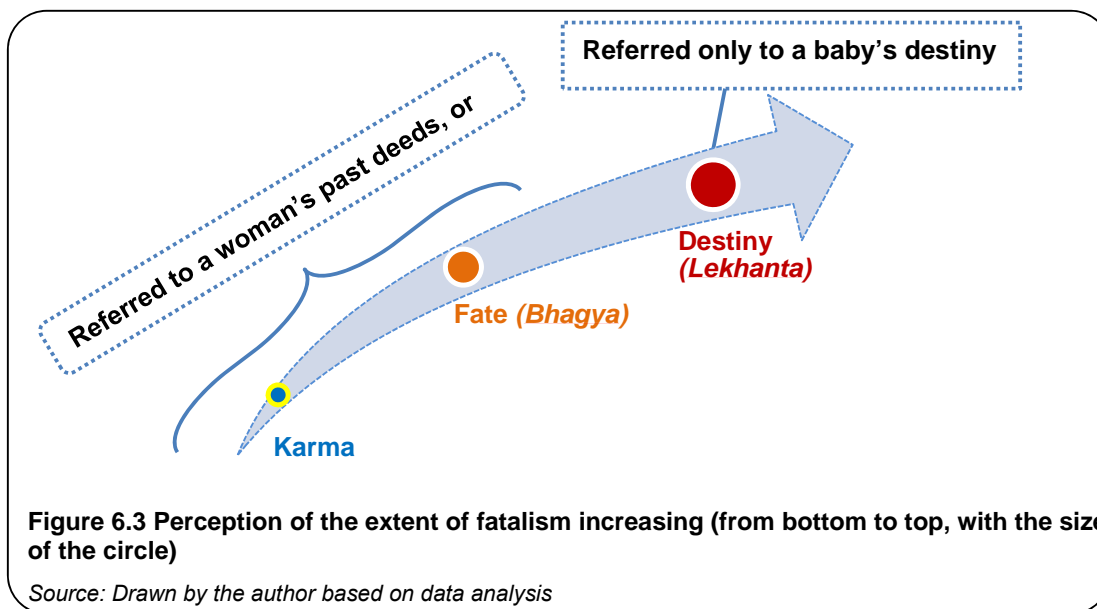
In these villages, *Karma* or fate as reasons for perinatal loss is linked personally to a woman's *Karma* or fate. It is believed that one's good *Karma* in the past yields good results. If one had bad *Karma* in the past, the results would be bad which s/he has to experience during the present lifetime. The story of Punchamaya shows how she related *Karma* and fate to her repeated pregnancies and the deaths of her babies.

I lost these babies (her three children). Had they survived, why should I have had too many births? I am unlucky, this is my fate (Bhagya); this is my Karma. (Punchamaya, a 35 year old mother)

Punchamaya is a 35 year old *Khasan* woman, illiterate and from a lower caste. She has six children: three boys and three girls. She lost a newborn, an infant and a toddler. At the time of this interview, Punchamaya was in the last month of her tenth pregnancy. Her husband is a local blacksmith. **[Box 6.19]**

By the word *Bhagya* (fate), participants in this study referred to the current state that a woman has been going through, and which is perceived as a result of one's *Karma*, therefore often used together with *Karma*. The use of the term 'fate' indicates a stronger perception about the lack of control over babies' deaths. Laldevi stated:

This place (house) has nothing wrong, no ghost/evil spirit (Lagobhago) here. We took the baby to a faith healer (Dhami). You know, during my pregnancy, the faith healer had already told me either mother or baby will suffer. The baby died because it was not in my fate (Bhagya) [pause]. We also treated him with medicines from a drug seller [But after permission from faith healer]. Yet, it did not work. I feel it was not in my fate. (Laldevi, a 17 year old mother)

Laldevi is a 17 year old *Khasan* girl, married at 16 and studying at grade nine. Her baby had a cough and cold, and was first taken to a faith healer. Later, when it was not improving, and the faith healer permitted them, they took the baby to a local drug seller for treatment. Eventually, the baby died on the 33rd day after birth. Laldevi's husband lives in a city far away from home, and is currently studying to become an auxiliary health worker. **[Box 6.20]**

Laldevi had a strong belief that her baby would not survive because of her fate. Like Laldevi, another participant Kushumkali (Box 6.17) did not see any possibility of preventing the death of a baby against her fate. She believed that baby loss was inevitable if its survival was not in one's fate. During conversation, Kushumkali used the term *Chado,* meaning fate in her local dialect.

How can we stop this (a death of a baby)? We can't prevent a man dying and a river flowing. If the baby is not in your fate (Chado), s/he will certainly die. Look, these other children, they are here. That baby was not in my fate, and passed away on the day after birth. (Kushumkali, a 31 year old mother)

Participants usually referred to fate as a woman's 'personal fate'. Only a few supportive family members related the loss of a baby to their collective 'family fate' similar to the notion of group or collective *Karma* (Krishan, 1997, p. 11; Neufeldt, 1986, p. 5). Krishnan referred to religious texts, which state that a person may suffer not just for his/her own *Karma*, but also for the collective *Karma* of his/her forefathers and other family members. Neufeldt explains collective *Karma* as being when an individual suffers due to the *Karma* of a group of people in the vicinity. In such a context, it is believed that *Karma* operates in interaction with others, thus an individual could suffer due to personal *Karma* as well as, what Neufeldt describes as 'group *Karma*'. Laldevi is among a

very few fortunate daughters-in-law to have a supportive family. It was evident during her interview that Laldevi's mother-in-law related the loss of her grandchild to their fate, not just to the personal fate of Laldevi. It was their collective fate, resulting from *Karma* of her family. Yet, it did not necessarily reduce their perception that fate caused the baby's death. Babies' deaths were rationalised as the results of their collective *Karma* and fate.

> *What to do [a sense of fatalism), it was not in our fate (Bhagya). It is not just due to her [Laldevi's] fate. We lost our grandson. (Laldevi's mother-in-law, a 52 year old woman)*

Bishnumaya (Box 6.1) perceived that it was her personal *Karma* which led her through three continuous losses, one in pregnancy and two after birth on the first day of life. Bishnumaya accepted the losses as her personal fate which she believed she could not change. Believing that this was her personal fate, Bishnumaya even suggested her husband to re-marry.

> *It is my fate [I lost these three babies]. I am unlucky; I have no secure future (Gharbar). I am not sure if my babies would survive if I had married another man. It is my Karma. Therefore, I thought, at least my husband will have a family legacy. I told him to marry another woman. (Bishnumaya, a 20 year old mother)*

Perinatal deaths due to a woman's *Karma* or fate are strongly associated with continuous losses, usually the loss of two or more babies. There is a strong sense of *Karma* and fate attached to a woman when they do not have a single surviving child as seen in Bishnumaya's case. After the continuous losses, Bishnumaya's family started believing that it must have been her *Karma* which was responsible for the loss of her babies.

A few women believed fate was not only a reason behind the deaths of their babies, but also a reason for any other consequences that they had to bear. The story of Sita revealed that she resorted to her fate when she lost her newborn baby, and when she felt neglected and abused by her husband. Sita went through her husband's abuse and torture during her pregnancy and after the death of her baby. She had to suffer ongoing emotional violence from her husband. However, Sita perceived that her sufferings were due to her fate and sought refuge in God.

> *You feel deep pain inside when someone this close [her husband] tortures you with such words. What to do, God didn't keep that baby alive. So what can I do? It was my fate (Bhagya). (Sita, a 20 year old mother)*

Sita is 20 year old, illiterate and a lower caste *Khasan* girl married at 18. Now, she is in her third pregnancy. She lost a newborn baby last year. Her mother had also lost five children, and could save only Sita and her sister. **[Box 6.21]**

Some women and families rationalised perinatal deaths as their babies' *Lekhanta* (destiny). Devkumari (Box 6.15), her sister-in-law and mother-in-law went through repeated perinatal losses. Her husband, an educated person working in public office, perceives that it was *Lekhanta* (destiny) for which their newborns died.

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> *…our two babies died after birth. What to do [there is no way]. No one can control these deaths. The ones, who are to die, will die anyway. This was Lekhanta (destiny) of these babies. The rest of our babies survived. Now, they are growing up. We have a grown up eight year old daughter, a young boy and a baby girl. (Devkumari's husband, a 29 year old father)*

I did not notice any gesture of disappointment in Devkumari, it was seen that the belief about destiny had led her to accept that the babies' death was inevitable. Her mother-in-law linked the babies to a cucumber (*Kakadi*), which could be picked from the kitchen garden before it is ripe.

> *I lost my own children, and also lost my three grandchildren. What disease did those little ones have? There is no other reason, just a destiny (Lekhanta, Marne Kal). Regarding the elder son's baby girl, I didn't know what had happened. I went inside the Gotha (the birth place), and then I knew that the baby had died. I don't know, it was neither heat (Taplagne), nor any other problem. The newborns are like cucumber (Kakadi), they could be picked up anytime as per God's plan. These deaths are as per God's plan, one God gave them and another God took them away. That is the fact behind these deaths. (Devkumari's mother-in-law, a 67 year old woman)*

During an informal chat in the village, a local faith healer commented that *Lekhanta* (destiny) results in babies' deaths before *Chhaith*. He excluded the babies dying in womb to the other causes such as mother's exhaustion due to work and lack of food *(Hanpiyera)*. He is certain that the deaths of babies after birth and before *Chhaith*, are due to *Lekhanta*. In the Hindu cultural belief in Nepal, the sixth day after birth is considered auspicious. It is believed that on this day, the goddess of destiny will write who and what the newborn will become in his/her lifetime. Families light a traditional earthen lamp *(Diyo),* and also put out a notebook and a pen wishing for a good luck inscription from the Goddess *Saraswati* (the Goddess of knowledge). However, villagers celebrate it as per their convenience, usually no later than the first month after birth.

> *When a woman is hungry, it affects her baby; we call it Hanpiyera (work exhaustion and hunger). The baby dies in the womb. If the baby dies before Chhaith (the sixth day celebration), it is due to Lekhanta (destiny). This is not due to anything related to mother, father and family. (Local faith healer, TH2)*

As well as stillbirths, neonatal deaths during a woman's confinement in the birth place, *Gotha*, usually up to three weeks are attributed to destiny.

The women and their families were more convinced about destiny as a reason for a baby's death when the baby died after seeking help from faith healers. It is evident that the women's perceptions about destiny were influenced by local faith healers from whom help was sought. Kanghmu (Box 6.13) stated:

> *I was worried about whether my baby would also die in this pregnancy. Last week, I contacted a faith healer (Dhami). He said, 'If children die even after my effort, it is due to their own destiny (Kalgati), they are destined like this. I can't stop them from dying. I can't save them'. Therefore, it is about their destiny (Kalgati). I will see how this pregnancy goes. (Kanghmu, a 25 year old mother)*

Kanghmu went to local faith healers before the death of her two previous babies. She is currently pregnant, and has already invited a faith healer to see if she could prevent the death of her unborn

baby. She related her previous losses and also the possibility of preventing the loss in future to the destiny *(Kalgati).*

To summarise this section, women's *Karma*, fate, and the baby's destiny are perceived to be important contributors to perinatal death. The perception of a lack of control over babies' deaths has been the strongest when the deaths are attributed to *Lekhanta* (destiny), less strong when one's fate is perceived to be the cause of the babies' deaths and the least strong when one's *Karma* is believed to have caused the deaths.

6.4 Discussion

This chapter has examined the religio-cultural determinants of perinatal survival and death in the contexts of remote mountainous villages of Nepal. Women and their families considered perinatal deaths (both stillbirths and neonatal deaths) as common experiences of their lives. The death of a baby before term *(Hunemahina)* was not considered a loss of a life. They believed God's will was a factor in health and sickness of mother and baby, and believed an unhappy God was a cause for different types of sicknesses among women and their babies. When a perinatal death occurred, it was perceived as inevitable and embedded in their religio-cultural beliefs of *Karma* (past deeds), *Bhagya* (fate) and *Lekhanta* (destiny).

The first theme of this study is: 'Everyone has gone through it': perinatal death as a natural occurrence. Perinatal deaths have been collective experiences, the experiences of everyone within the family (mother, mother-in-law, sister and sister-in-law), other relatives, and across their neighbourhood communities. This common experience has shaped construction of perinatal deaths as inevitable experiences. Experiences are viewed as sources of knowledge in the social constructionist view (Kolb, 2015). In this study, the past experience of women and experiences of older family members construct knowledge of younger women. Women considered the persistent occurrence of perinatal deaths as a generational continuum, bound to occur with everyone. Such perceptions of women are reassured further by the experiences of baby losses in the households of female community health volunteers and local health workers.

This study identified acceptance as the norm when the death of a baby occurred before full-term *(Hunemahina)*, and during a mother's and baby's confinement after birth. Confinement is due to the ritual pollution *(Chhuhi)* in which a mother and her baby stay in *Gotha* during and up to three weeks after birth. In this study, the women's and their families' description of perinatal deaths as *Pakhalajane,* or *Aadanjhadne* indicates premature deaths before full-term. These are not lives lost, not the death of babies. These are perceived as if women were evacuating their bowel, perceived in the same way as a diarrhoeal condition. Stillbirths *(Hudaimareko)* and neonatal deaths during ritual confinement are of less importance, and hence not considered worthy to report and mourn. Such perceptions are similar to the Hmong women's constructions of stillbirth and neonatal deaths

as non-significant events (Liamputtong, 2000). A recent study from the rural Amhara and Oromiya region of Ethiopia (Sisay, Yirgu, Gobezayehu, & Sibley, 2014), a study from Tanzania (Haws et al., 2010) and a study from Uganda (Kiguli et al., 2015) described similar perceptions of low social significance given to stillbirths and neonatal deaths, considered as non-human deaths, spirit deaths, or occurrences not worthy of sharing with others.

Some studies suggested stigma is one of the key factors making stillbirths and early neonatal deaths invisible in the communities (Frøen et al., 2011; Haws et al., 2010; Lawn et al., 2016). They remain unchecked in communities, and underreported from official records. These studies describe that people avoid talking and sharing about such deaths particularly due to stigma. However, in the present study, perinatal deaths are not found to carry any stigma. In the context of the present study, the construction of perinatal death is seen as a mere biological loss, and not the loss of a social individual, and has paid no attention towards improving perinatal survival, and the survival of the child before it enters home from *Gotha* (*Gothabhitrai Mareko*). These are considered simply of low importance to the women and their families, perceived as an inevitable occurrence as a generational continuum. Loss of these early lives (foetus and newborns) is a question of a non-value attached to their personhood, reminiscent of Aries' argument in relation to the social construction of childhood that parents will not respond too emotionally to infants who might die early, and hence consider them as "neutral" (or non-persons) for some time after birth (Aries, 1962).Perinatal deaths do not receive any ritual significance. According to Hindu belief, the death of a child who had gone through a ritual of wearing holy thread *(Bratabandh)* receives full social significance, requires ritual funeral ceremony, a 13 day mourning *(Kaajkriya)*, considered as *Jutho* (barred from taking salt, meat) within families and their relatives, and *Barkhi* (annual ritual on the memory of deceased family member). Stigma related burden is much less in these communities also due to beliefs about God and *Karma* in causing illness and deaths. This indirectly indicates a level of acceptance towards perinatal deaths to such an extent that parents and families consider no reason to take any preventive measures.

The second sub-theme of this chapter is *Dewata* (God) as a factor in health and sickness: a cause and a means to overcome sickness in mothers and babies. *Dewata* is the generic name of a range of Hindu Gods and Goddesses. This is a common cultural phenomenon also in the *Lama* community although they follow the Buddhist faith. The present study explores the beliefs of the women and their families that God exerts a powerful influence on their perception of the causes of illness and response to recovery. Belief in God is women and families' worldview affecting every aspect of their day to day lives, and not just a symbolic God *(Deuta)* kept inside their house (Kaphle et al., 2013). Such a worldview in the villages shares similarity with the traditional Akan religious worldview about health and sickness as described in a study from Ghana (Awuah-Nyamekye, 2010). The indigenous Akan people in Ghana, and people in the Tehuledere region of Ethiopia (Kahissay, Fenta, & Boon, 2017) believe in a host of human and non-human and

supernatural beings (God/*Allah* and deity) having the capability to affect their lives positively and negatively. The human agents comprised witch, sorcery, and non-human agents included ghost, ancestor, and evil spirit. The present study also identified that common illnesses of mother and baby during pregnancy and after birth are believed to be due to the displeasure of God. Human, non-human agents and supernatural beings similar to what was found in the Ghanan study, are viewed as due to an unhappy God. These are believed to operate in different forms through human, non-human agents under the generic name *Dewata*. They have their own illness language broadly categorised into two types: (i) illness solely attributed to God, where only shaman healings, prayers, animal sacrifice, offerings, worships, mantra recitations, sprinkling holy waters, exorcism and amulets are considered to cure; and (ii) illness in which God is attributed as the cause, yet the care is sought combining the former plus using local herbs. A range of their illness languages is characteristic of different medical conditions, such as *Banlagne* (an acute attack of rainbow, characteristic of neonatal tetanus, asphyxia), *Mojhlagne* (characteristic of severe anaemia and low nutrition during pregnancy and repeated premature deaths), *Taplagne* (characteristics of infection), and *Sardilagne* (characteristic of pneumonia). In both types of illness, local faith healers are the key providers who practice as both shaman healers and local herbalists. They are believed to possess Godly powers, and able to invoke the mercy of God. It was found that when they did not have a clue to what type of sickness had happened to the baby, mothers called it *Dewatalagne*, a common term to indicate influence of a range of different Gods. It is not in the scope of this study to go into further detail of the locally perceived different sickness types. For this, I recommend further ethno-medical investigations about perinatal sickness in the mountainous villages of Nepal.

Beliefs about perinatal sickness and deaths due to supernatural forces are also described by previous studies in Africa and among Hmong women (Denham et al., 2010; Liamputtong, 2000; Sisay et al., 2014). The present study adds that not only baby's illnesses but also mother's common illness, birth complications including contraceptive norms are considered to be in God's control in the villages. The frequently reported illnesses believed due to God's influence include: swelling of legs and convulsions during pregnancy and after birth, lethargic and weak mother during childbirth, birth complications such as prolonged birth, postnatal bleeding and breech presentation, inability to secrete breastmilk, newborn not able to suck the breastmilk, difficulty in breathing, lethargic baby, and bleeding from umbilicus. Birth complications which require skilled attendance or immediate referral are believed to be God's wrath and the people invited faith healers to do exorcism, prayers and offerings to God up until the last minute. It is believed that for a sickness due to God's wrath, going to health facilities might negatively impact on the cure; this belief is even stronger in *Lama* people. Health workers are consulted when none of these work, usually after permission from the faith healers, yet faith healing is simultaneously done.

The third theme in this chapter is: *Karma*, *Bhagya* (fate) or *Lekhanta* (destiny): three ways of rationalising perinatal deaths. The concept of *Karma* and its influence on women's perception and

acceptance of perinatal deaths is widely prevalent in the study villages. Fatalism has been described by studies in different South Asian countries, such as a study in Pakistan (Kayani, King, & Fleiter, 2012) which described fate often attached to the occurrence of road traffic accidents and deaths, and fatalism as a key factor to continued risky road use behaviour among the people. God was perceived to map out fate, and such perception is described as a barrier in promoting road safety messages. An Indian study (Singh, Sinha, Banerjee, & Jaswal, 2013b) showed that belief in *Karma*, sin and punishment by God were described as reasons for Leprosy by about two-thirds (65%) of the study participants. Fatalistic beliefs about infant deaths were identified by other studies such as by Rusman et al. (1999) in the upper Lombok region of Indonesia where infants died due to simple treatable conditions. Fatalism surrounding treatment of neonatal infections (Simen-Kapeu et al., 2015), health care for small and sick newborns (Moxon et al., 2015a) and stillbirths (Frøen et al., 2011) have been frequently mentioned, but not thoroughly explored in a specific socio-cultural context as the present study does.

In the study villages, the religio-culturally based beliefs of women's *Karma* (past deeds) and fate have intensified the acceptance and fatalism about perinatal death. Due to such beliefs as reasons for babies' deaths, women and families have remained passive about seeking health care during perinatal sickness, and hence about preventability of these deaths. One of the most frequent phrases that appeared during interviews and informal chats about what s/he thinks that his/her baby died, was 'What can we do? This was my *Karma (Ke Garne, Mero Karma Yestai)*, reflecting a deeply rooted fatalistic belief. Fatalistic expression is seen even stronger when women rationalise their baby loss as *Lekhanta* (destiny), which they often meant as the baby's personal destiny, thus perceiving total control on baby's death, usually those deaths before *Chhaith*, and deaths during the postnatal confinement. During this confinement, both mother and baby remain in the cowshed, and are less likely to access any types of health care. The concept of *Karma* has trapped people in a vicious cycle of rationalising their babies' deaths as *Karma*, waiting for the baby to be healed by pleasing God, and also accepting the deaths as *Karma*, fate or destiny.

Max Weber, in his book 'The Religion of India: Sociology of Hinduism and Buddhism' described the fundamental values of Hindu and Buddhist religions: *Karma* and reincarnation as doctrines of fatalism (Weber, 1958). Weber describes that these values do not talk about this world, but about a supernatural world, and point to the past or future lives. Like Weber's interpretation, the village women and families have been deeply affected by these beliefs. It is difficult even to distinguish these as religious beliefs or cultural beliefs because they are deeply embedded cultural beliefs and values in the villages as part of their worldview as earlier discussed. In this thesis, they have been together termed as religio-cultural beliefs. Yet, in the present study, it is argued that the perception of *Karma* and persistent occurrence of perinatal deaths is the result of their false *Karma* consciousness. Although Weber's interpretation matches the reality in the villages, the concept of *Karma* is viewed as a universal law of justice, a law of cause and effect. *Karma* is not meant to

create enduring inequity or injustice which the women face in the study areas of Nepal. In Bhagavad-Gita, the fundamental religious textbook of Hinduism (Prabhupada, 1972), *Karma* is described as a great art of performing action in realms of thinking, speaking and acting. It is not so much about the past *Karma* of previous lives, it is mainly about the present *Karma* upon which an individual is considered to have control, hence bringing the power into an individual's authority and will. Therefore, the purpose of *Karma* doctrine is described to make one aware about their actions and to bring back the realm of cause and effect into his/her control rather than relying on fate or passively waiting for past *Karma* to map out one's fate. It is meant to empower one from weakness, pessimism and escapism, and to remain firm as a *Kshetriya*, a warrior who is mindful of the realms of his actions: thoughts, speech and actions. The values that Weber described as fatalistic are referred to teach the art of living, and to liberate one's life. On this basis of constructive criticism, I view that an active collaboration could be sought with religious leaders and faith healers to correct the misconception (or general popular conception) of the fundamental values and thereby empower women and families. This argument is also seen to resolve the dilemma of respecting religio-cultural values and avoiding the false perceptions and associated fatalistic views which are the popular conceptions rather than scriptural ones.

A range of studies discussed religious affiliations related to, or associated with, health outcomes both positive and negative (Alves, Alves, Barboza, & Souto, 2010; Ellison, Hummer, Cormier, & Rogers, 2000; Gyimah, Takyi, & Addai, 2006; Koenig, 2012; Williams & Sternthal, 2007). The impact of religion in health is described mainly through two pathways: by affecting individual beliefs and norms related to health practices, and by increasing people's social capital/connectedness and empowering people to effectively utilise relationships and resources for their health and wellbeing. Positive health outcomes are described mainly in supporting people to live and cope through the tragedies of bereavement, HIV/AIDs, non-communicable diseases such as cancer, positive mental health and reduced addiction/substance abuse and crime. Negative outcomes are about not seeking or delaying seeking medical care due to rigid religious beliefs.

In the present study, the acceptance and fatalism related to religio-cultural context is an emergent theme analysed through the women and families' narratives regarding the experiences and beliefs about stillbirths and neonatal deaths. Therefore, one may argue that the religio-cultural beliefs of *Karma*, fate and God have healed the wounds of women and families and any potential psychological burden from experiencing perinatal losses. However, the continuous human losses cannot be justified on the ground of human rights, the survival right to life of every child (UNICEF, 1989), and the fact that almost all of these deaths are preventable. Addressing the false perceptions of *Karma* and God with due respect to local culture seems to be the only way forward.

This study has revealed the religio-cultural contexts related to the acceptance and fatalism about perinatal deaths as a powerful hidden force to perpetuate the risk of ongoing perinatal deaths in

the mountain villages. A comprehensive understanding of such a context has strong policy implications to tackle the high prevalence of perinatal death in rural and remote areas of Nepal. Current perinatal survival policy and practices in Nepal describe a dominantly bio-medical discourse around improving survival with less regard to the evidence regarding the local socio-cultural contexts of the mountain villages (Chapter Five). The policies are influenced by overwhelming national and international evidence on epidemiology and bio-medical risk factors of perinatal deaths: stillbirths (Lawn et al., 2011; Lawn et al., 2016), and neonatal deaths (Lawn et al., 2014; Lawn et al., 2005). The available interventions are largely bio-medically oriented, aimed at preventing deaths from sickness, complications of prematurity, infection and asphyxia, based on a Western medical viewpoint of the causes. Contrastingly, the lay constructions and beliefs explored surrounding perinatal sickness and deaths, view loss of early life as a generational continuum and common experience; attribute perinatal sickness and cure to God; and rationalise perinatal deaths as *Karma*, fate and destiny. These views are more likely to prevent people from seeking formal health care. These findings strongly indicate a need for bridging professional discourses with such lay discourse. The health care systems and policies need to acknowledge and negotiate this in their actions to improve perinatal survival.

Kaphle and colleagues described God shaping women's cultural perceptions of safety about childbirth tradition in mountain women of Nepal (Kaphle et al., 2013). The present study adds that the belief in God's influence in health and sickness has been a predisposing factor to prevent any perceived medical severity of illness by the families during a mother's and baby's sickness and birth complications. Eventually, this influences families in choosing faith healers (Kroeger, 1983). They choose the traditional healers as the medium to invoke God, thus delaying, and often preventing them from seeking skilled and timely care from the health care system. It appears that Kaphle and colleagues limit their discussion to accepting the popular conception of God without further questioning it. However, the present study speculates that it is a false popular conception of God in their religio-cultural context, most likely started as a moral order to instil discipline which became reinforced by faith healing practices.

It is the same with the women's belief in *Karma*, the fundamental religious value of Hinduism and Buddhism. As argued above, the perception of these religious beliefs about God and *Karma* are the popular conception rather than a scholarly conception which mainly influences local communities' perceptions and practices in relations to perinatal death. Taking religio-cultural determinants into consideration during policy formulation and programme planning is pivotal to ensure community acceptance and participation. To bridge community members with the health system, many interventions attempted to engage with trusted members of the communities such as faith healers and religious leader. An example of such interventions is in Indonesia where professional midwives grouped to work in partnership with traditional birth attendants to provide emotional and cultural support to local women, refer pregnant mothers, and provide postnatal

services in the communities (Hermawan, 2016). A similar approach of partnership between traditional birth attendants and auxiliary nurse/health worker has been found as an effective means of community engagement and advocacy to increase the use of birthing sites/facilities by indigenous people in Guatemala (Stollak, Valdez, Rivas, & Perry, 2016).

There has been a growing realisation for the need to integrate spirituality in medicine/health care (McCormick & Min, 2014; Sorajjakool, Carr, & Nam, 2010). This has been considered especially important in addressing the religiosity of patients in societies with diverse faiths. McCormick and Min suggest that a spiritual history should be taken of every patient as a part of his/her general medical history so that any religious/cultural/spiritual beliefs can be understood, and utilised as a resource for the health care, support and wellbeing of patients. Although the study villages are not open societies with diverse faiths, the engendered context of the perception of God as an aetiology of sickness, and the religious value such as *Karma* being seen as a reason for their perinatal deaths, indicates a lack of consideration of religio-cultural factors in the health system. It is imperative for primary health care workers to understand and address such beliefs in the communities in a culturally competent way, not merely focussing on instruction about danger signs during pregnancy, birth and postnatal period to a handful of women coming to health institutions. The present study indicates that it would be imperative to revise the entire curriculum for the training of doctors, nurses, midwives and health workers to include training to address religio-cultural issues in health in specific communities.

A range of studies (Bhutta et al., 2014; Bhutta et al., 2011; Darmstadt et al., 2005) have suggested a long list of family/community and health facility based interventions to reduce ongoing stillbirths and neonatal deaths. Although these interventions are typically characterised as family and community-based, they are more likely to be prescriptive without an understanding of contextual factors and level of women and families' awareness in the communities. The construction of perinatal deaths as natural events reflects that women and families do not see any point to seeking health care. On the other hand, it also suggests that they are not being sensitised for health behaviour change, even though the national policy strategies (see Section 5.3, Chapter Five) are aimed at such behaviour change. The key bio-medical focus of the discourse surrounding causes of stillbirths and neonatal deaths (infection, asphyxia and intrapartum complications) intends to limit the content of behaviour change to conveying the knowledge of danger signs (during pregnancy, birth and postnatal) to mothers. Rather, women and families should be invited to question their constructions related to personhood status of a stillborn and a newborn baby (loss of early lives as natural events of low social significance), illness causation (God) and their rationalisation *(Karma)*. Assisting women and families this way should be a key focus of family and community-based behaviour change interventions and birth preparedness packages. Otherwise, the prescriptive long list of interventions or intervention packages (newborn/child intervention packages) alone are likely

to be much less effective, and this could be one of the reasons for the low impact as seen from Nepal's newborn intervention package (Paudel et al., 2013a; Shrestha et al., 2015).

The apparent invisibility of these perinatal deaths in the remote mountainous villages is reinforced by the negligence of the local health system in recording and reporting them, and the indifference of policymakers, in particular towards stillbirths (see Chapter Five, Section 5.3). Further, not only do women in the communities have low concerns about perinatal deaths, the female community health volunteers and some local health workers also perceive perinatal deaths as trivial. The National Neonatal Health Strategy of Nepal (MOHP, 2004b) and the Maternal and Newborn Health long-term plans (MOHP, 2002, 2006b) consider female community health volunteers as pillars of the community health system in the country. However, the health volunteers are not mobilised to engage with women and families, and to keep records of, and report perinatal deaths in the village health facilities. It was noted that the health volunteers did not perceive the importance of reporting unless it was a late infant or an under-five death. The cultural context has influenced the volunteers to perceive stillbirths and deaths of newborn babies while in *Gotha* (during ritual confinement) as not worth reporting.

The findings from this study are consistent with a study undertaken by Målqvist et al. (2008) which identified the invisibility of neonatal deaths in a northern province of Vietnam due to a dysfunctional reporting system, which officially reported a neonatal mortality rate (NMR) of four (per 1,000 livebirths) against an NMR of 16 identified in their study. They also found that the NMR varied between 10 and 44 across the districts in their study province. Although the present study is a qualitative one, where mortality measurement is not a goal, I observed a huge discrepancy between the officially reported number of perinatal deaths and the participants' reports. During the five months of the fieldwork for this study, in the two study villages, 42 women voluntarily reported 49 perinatal deaths (16 stillbirths, and 33 neonatal deaths) occurring in the last four years, a majority of them in the last two years. Whereas, the local health institutions in the two study villages reported only five neonatal deaths including their verbal reports, and only three in the local records. The sum total of deaths reported by participating women from two study villages in this study provided a larger number of deaths than the sum total of the perinatal deaths reported by the health system for the last four years across the 24 villages in the district (see Chapter 4, Section 4.3.3). A study from India also described that reporting the actual number of deaths is avoided as it could be judged as poor performance by the health care providers (Bang et al., 2002). The present study suggests that the invisibility has been reinforced by the fatalistic attitude towards perinatal deaths, both in the community and in the local health system. This underreporting of perinatal deaths is related mainly to the low social significance accorded to perinatal deaths due to the deeply rooted religio-cultural beliefs of acceptance and fatalism. It is inferred that the service providers and female community health volunteers did not find it worth inquiring and reporting perinatal deaths. This systemic fatalism (including by community health workers) has contributed to

the invisibility which is certain to reduce the efforts of implementing perinatal survival programmes by the local health system. Such rural areas as in Nepal are therefore likely to be overlooked.

The 2015 UN estimation shows a nationally reduced neonatal mortality rate of 22 per 1,000 livebirths, (UNICEF, 2015b) and stillbirth rate 23 per 1,000 total births in Nepal (UNICEF and WHO, 2015). Such estimates are important, yet, considering an equity focus in underserved subregions within a country, the present study cautions that by using these national level data, the national government and its policy makers would be merely scratching the surface of the overall burden of perinatal losses and miss the huge burden which exists in the rural mountainous villages. Global and national mortality estimates are helpful to show a pattern about mortality and health care utilisation. However, relying only on the national rates and estimates without having in-depth contextual investigations will prevent help from reaching every newborn and stillbirths in the underserved regions. Focus on equity, quality and coverage to reach every mother and newborn, is a current national and international priority (Every Woman Every Child, 2015; WHO, 2014c). Therefore, this study also suggests local level surveys in such remote and disadvantaged regions to identify a real picture of deaths at the local level, without consequently missing the within country regions which have a high mortality burden. This can contribute to ending preventable deaths of babies before and after birth as is the aim of national and international policies.

The present study findings reflect the voices and beliefs of women and families from one of the most underserved and disadvantaged part of Nepal, which also receive a very low research priority within the country. The voices of women and their families with regard to perinatal survival has been unequivocal priority after the 2012 'born too soon' movement, and the Every Newborn Action Plan which has introduced raising the voices of parents and families as one of the five key strategic activities of the plan (WHO, 2014c). Lay perspectives are considered crucial in public health research (Popay & Williams, 1996); these perspectives shape what people do and why (Popay et al., 1998). In-depth understanding of how women and their families perceive and describe their experiences of perinatal deaths is a methodological shift from surveys, verbal autopsies and recently emerging interest about social autopsy. A large body of evidence in perinatal survival research is based on structured surveys and verbal autopsy (WHO, 2012) to describe a pattern of mortality and service utilisation across socio-demographic determinants and medical causes of deaths rather than to examine the influence and interactions in socio-cultural contexts that leads to perinatal deaths. Recently an interest is growing about the need for social autopsy (Waiswa et al., 2012). I found that in-depth qualitative interviews with women and their families experiencing perinatal deaths became possible and an appropriate way to uncover the influences in local socio-cultural context that contributed to the poor perinatal survival. In addition, interviewing women and families in the villages made them feel respected and valued their experiences.

6.5 Conclusion

After analytically studying the beliefs and experiences of the women and their families with respect to perinatal sicknesses and deaths in the mountainous villages of Nepal, this chapter comes to the conclusion that these events are constructed as natural occurrences and linked to religio-cultural beliefs such as *Dewata* (God), *Karma* (past deeds), *Bhagya* (fate) or *Lekhanta* (destiny). Such religious beliefs have made people fatalistic, causing them to believe that they lack control over their own and their babies' sickness and death. Because they believe God and Karma are the cause of such events they seek help from those whom they believe could intervene such as faith healers, rather than going to a health facility. The continued presence of fatalism also raises the question whether any perinatal survival intervention has ever penetrated the rural communities and villages. The findings of this study strongly indicate the need to invite discussions on the construction of personhood and social significance of foetus and newborn babies in the current behaviour change discourse. The findings further call for initiating partnerships between medical health practitioners and faith-based healers and religious figures at the local primary health care level. Current policy documents lack consideration of such religio-cultural determinants. Future policy and programmes must strongly incorporate such determinants to prevent ongoing mortality in the mountain villages.

The next chapter discusses gender related cultural contexts of poor perinatal survival in the study villages.

GENDERED CULTURAL CONTEXT OF MOTHERHOOD EXPERIENCES AND PERINATAL SURVIVAL

The previous chapter discussed fatalism and acceptance of perinatal deaths amongst women, families and communities living in the villages studied in this thesis. A range of religio-cultural factors has influenced the attitudes of women and their families, in perpetuating fatalism and the acceptance of perinatal deaths. Collective experience of everyone and shared experience of perinatal deaths over generations have shaped the perceptions of women and families to regard perinatal deaths as inevitable phenomena. The belief of *Dewata* (God) both as a cause of, and a solution to alleviate, sickness amongst mothers and babies, has been a crucial factor in making perinatal deaths almost always acceptable. The rationalisation of perinatal deaths as the results of *Karma* (past deeds), *Bhagya* (fate) and *Lekhanta* (destiny) has stopped the community from seeking modern measures to prevent perinatal deaths.

This chapter explores the influence of the gender-related cultural context on motherhood experiences leading to poor perinatal survival in the villages. This is undertaken by an examination of the context within which women and girls live and its influence on pregnancy, childbirth experience, and the postnatal care. The following emerging themes (Figure 7.1) are discussed in this chapter.

7.1: Gendered social construct and vulnerability for poor perinatal survival: child marriages, son preference and repeated child bearing

Motherhood

An adolescent girl and her *Gharbar* (home settlement)

7.2: Pregnancy and childbirth in intra-familial dynamics of relationships and power

Work

7.3: Perception of birth as a polluted event: birth in *Gotha* (cowshed), and giving birth alone

A daughter-in-law within a family

Gotha (cowshed)

constructs of poor perinatal survival

Source: author based on data analysis

A woman & baby during and after childbirth

7.1 Gendered Social Constructs and Vulnerability for Poor Perinatal Survival: Child Marriage, Son Preference and Repeated Childbearing

This section describes how the construction of 'settling a home for young adolescent girls *(Gharbar)'* has driven early marriages, early and repeated childbearing and consequent baby losses. This elucidates the significance of gendered cultural beliefs and norms to perpetuate poor perinatal survival. The first ground-breaking international conference on population and development (ICPD) held in Cairo in 1994 identified couples' reproductive rights, which is to empower both men and women to decide the number, timing and spacing of children in mutual partnership (UNFPA, 2014). After more than two decades since the ICPD, women in the study areas appear to have no reproductive rights. The gendered construct riding on male supremacy has been the underlying force to encourage early marriage, early childbearing and to consider pregnancy and childbirth as the women-only duty.

7.1.1 Child Brides, Child Mothers and Perinatal Deaths: A Common Phenomena

Child marriage, early childbirth and subsequent perinatal deaths are common among the majority of the participants in this study.

Child marriage, a common occurrence

Since 1963, Nepal's legislative innovation prohibited child marriage (Human Rights Watch, 2016). The minimum age at marriage for both girls and boys is 20 years. According to the existing law, parents who marry their daughters or sons before the age of 20 are subject to punishment with a fine of up to Nepalese Rupees 10,000 (about AUD 125) and up to three years imprisonment. Despite the child marriage act and its legal punishment for non-compliance, parents continue to arrange marriages for their daughters before they are 18 years of age.

A majority of study participants (38 out of 42) were married and had their first birth before the age of 18, with ten of these 42 having married at or before 14 years of age (Appendix 4). From the viewpoint of women and their families, early marriage is not considered a matter for concern and the majority of participants evidently did not regret getting married early. Penghmu, a young girl with an experience of baby loss from her last pregnancy, viewed early marriage and child bearing as normal and a common practice in the village.

> *I gave birth at 16. I don't think I am very young to give birth. Others gave birth at 14 and 15 too. Therefore, I think it is okay to give birth at my age. (Penghmu, a 16 year old mother)*

Penghmu is a 16 year old girl, illiterate, lower caste and from the *Lama* community. Penghmu got married at 14. She lost her baby last year on the first day after birth. **[Box 7.1]**

Binita, another participant age 20, has a baby boy, and is currently pregnant with her fourth child. Although Binita was not concerned about her young age as a factor in her two baby losses, her husband reflected on the impact of young age and the consequence of Binita's fall in the eventual loss of the first baby during pregnancy.

> *My wife was very young at marriage. Now, she is just 20 years old. We lost two babies; we*
> *have only one baby. Sometimes, I think it might be her young age. She did not share it*
> *sooner when she felt sick during her first pregnancy. She did not tell me about her fall on the*
> *way home from farmland. I knew it after a week. We went to hospital but could not save the*
> *baby. The baby was already dead. (Binita's husband, a 26 year old father)*

Binita is 20 years old, went to school up to Grade Three. She got married at the age of 14. Binita lost a baby in the seventh month of pregnancy, and another infant on the 45th day after birth, who was admitted to hospital from the third week after birth for pneumonia treatment. Her husband is 26 years old. He is a labourer. **[Box 7.2]**

Laldevi (Chapter Six, Box 6.20) is 18 years old, studying in grade nine at a local secondary school, who felt sad about her early marriage and childbearing when she lost her baby. Laldevi was married at 16 and became pregnant soon after marriage.

> *I pray to my Dewata (God) not to bring to anyone the situation like mine. Let everyone save*
> *his or her babies. I got married soon (Bhagi Bibaha), disturbed my education, and at the end*
> *lost my baby. I am feeling alone. (Laldevi, an 18 year old mother)*

Laldevi had *Bhagi Bibaha*, a system of marriage at a young age in the local culture. Among the study participants, there were many others (Appendix 4) who had a similar experience of *Bhagi Bibaha*, early childbirths and subsequent baby loss.

Transition in marriage practices, but child marriages still continue

Marriage practices have changed in many parts of Nepal, particularly in the urban areas with a rise in the age of marriage of both males and females. Nationally, the mean age at marriage for girls was 15.5 in 1961, which increased to 19.5 by the year 2001 with a key change among urban residents and educated females (MOHP, 2011). Now, there is an increasing trend of love marriages (self-arranged marriages) in the plains as well as hilly areas but child marriages have not stopped, particularly in the rural areas and among the disadvantaged, indigenous and scheduled caste groups (Human Rights Watch, 2016; Maharjan, Karki, Shakya, & Aryal, 2012).

Despite the legal provisions against early marriage as stated above, such early marriages, especially for girls are culturally acceptable. In the past (until about 25 years ago), there used to be consensual marriages with a parental cultural contract, similar to an engagement, between the bride's and groom's families—locally called *Tike Bibaha.* Such marriages usually took place when a daughter reached seven years of age. A formal cultural ceremony was organised after their daughters reached about 11 years of age, the age that she is perceived as being ready to leave her parents' home. Over the last few years, such practice has changed from early age cultural

contracts to *Bhagi Bibaha*, which is a growing culture of marriage at early and mid-teenage years of the girl and is held usually without a cultural ceremony, often kept secret from the police and local political activists. The boy and girl meet each other briefly, and the girl goes to stay at the boy's house. They are then accepted as a formally married couple. The marriage ceremony if organised, is usually kept private between the bride's and the groom's family, or sometimes shared only among their close relatives and neighbours. Although nowadays early age parental contracts for marriage *(Tike Bibaha)* are rare, *Bhagi Bibaha* at young ages (14 or less) is a growing trend in the villages. One of the local community health workers said:

> *The national government introduced the child marriage act. According to this, no one should marry before [age] 20. However, this doesn't work here. Before, there used to be marriages after early age parental contracts (Tike Bibaha), now it turns into secret marriages of young adolescents without a cultural ceremony (Bhagi Bibaha). (Local community health worker, HSP12)*

Interviews with the study participants revealed that some parents even move to nearby forests and farmland at high altitudes *(Lekha)* to secretly arrange the marriage for their young daughters.

Bhagi Bibaha is common also because it is financially less burdensome on both the boy's and the girl's families. Dowry is a serious issue for a daughter's marriage in the southern plains region of Nepal (Karki, 2014), but it is less commonly practised in *Bhagi Bibaha*. From the point of view of a boy's family, in addition to dowry, there is a work expectation from a daughter-in-law in that she is expected to help with everyday household and agricultural chores. In addition, there is no requirement for elaborate ceremonies in *Bhagi Bibaha*, which saves the families of both the bride and the groom large sums of money on expenses related to traditional marriage ceremonies.

During informal chats in the villages, I identified other factors such as youth clubs and growing use of mobile phones as factors which encourage adolescents' romantic relationships and adoption of *Bhagi Bibaha*. Although the youth clubs were introduced to increase awareness in preventing child marriages, in fact they are seen to encourage *Bhagi Bibaha* among the young club members. I met a local youth club president, not yet 18, who married a club member, a girl younger than him. However, the use of mobile phones was a factor encouraging *Bhagi Bibaha* only in the first village, which is located near the district headquarters.

Notwithstanding the legal minimum age at marriage, *Bhagi Bibaha* provides parents with the opportunity of continuing with child marriages. These marriages at early ages are usually not registered officially to avoid legal punishments. Similarly, births of children and their death occurring in such early marriages are also not registered. A local journalist noted:

> *They have already had children. They do not register births and deaths of their babies. Neither are their marriages registered. They go for registration only when they are above 20. (Local journalist, SH9)*

Perception of an adolescent girl as ready for marriage and bearing children after her first menstruation (locally described as '*Gotha Pasne'*), and less parental control on the adolescents mainly in lower castes are seen as factors encouraging *Bhagi Bibaha*.

> *Adolescents from the lower caste community meet for local folk singing and dancing (Deuda) from young ages. They are perceived ready to marry and give birth after their first menstruation (Gotha Pasne), and this also allowed more freedom to participate in singing and dancing. I think that is a reason for child marriage. They know each other and end up with Bhagi Bibaha. (Senior Auxiliary Nurse, HCM1)*

After menarche, parents, neighbours and close relatives believe that their daughters are mature enough for marriage which allows them a freedom to attend group singing and dancing events, and therefore a greater chance of getting a partner for *Bhagi Bibaha.* However, such freedom is seen to be controlled by the parents in upper caste families because they have a fear of whether their girls would run away with lower caste boys. This fear was one of the reasons for early age parental contracts for marriage *(Tike Bibaha).* Parents do not appear to be directly involved in *Bhagi Bibaha*, but they accept it as this eventually meets their desire to settle their daughters' *Gharbar* (described in the section below) and made them feel secure about their daughters' welfare. Such marriages are also influenced by the boys' families who want daughters-in-law as soon as possible. It was observed in their conversation that they are happy about *Bhagi Bibaha*.

> *In the past, in our time we didn't have Bhagi Bibaha. Now, they just do it. A boy and girl meet each other, boy tries to persuade a girl, and the girl comes to stay with him. That's how a girl gets a husband. My daughter-in-law also came to my home by Bhagi Bibaha [he smiles]. (Ramkali's father-in-law, a 61 year old man)*

Ramkali is an 18 year old girl, illiterate and married at 14. Her husband is a student, currently studying a Bachelor's Degree. Two years ago, she lost her newborn baby, and already has a six month old baby boy from her second pregnancy. She is currently pregnant with her third child. Ramkali's father-in-law is a local health management committee member**. [Box 7.3]**

Settling 'a home for daughter (Gharbar)': a hidden motive for child marriage, early childbearing and repeated pregnancy

Settling a daughter—known locally as *Gharbar* is a gendered construction related to a young adolescent girl's marriage, childbearing and her settlement in her in-laws' home. A girl is perceived secured and settled when she is married, gives birth early and has a surviving child, preferably a baby boy. The participants described settling their daughters down with a home and a husband— girl settlement— as a driving force for early marriage. To settle a home, young brides get pregnant and bear children frequently, particularly when the children do not survive. Bishnumaya (Chapter Six, Box 6.1) described that she became pregnant with short spacing between births, when she lost her three babies one after another. In less than five years of her marriage, she is now pregnant with her fourth child.

> *First time my baby was born dead. Last year, I gave birth to another baby boy, but the baby died. Therefore, I became pregnant soon after this. This year I gave birth a third time, another baby boy; this died too. If both of these babies had survived, one baby would have been able to walk around, and another could have been sitting and standing on support. I lost babies all these three times. Therefore, I became pregnant soon after (Khata Khattai Sutka Base). (Bishnumaya, a 20 year old mother)*

Bishnumaya commented on her parents' concerns about her settlement *(Gharbar)* when she did not become pregnant soon after her third pregnancy. She has lost her confidence about whether she will be able to save a baby from the current pregnancy. She first became pregnant very soon after her marriage and for the second and third pregnancies, she became pregnant within four months of giving birth, as the babies died very early, she did not breastfeed and was able to conceive. Although Bishnumaya and her husband wanted to have another baby, she could not conceive sooner than 10 months after the loss of her third baby. Her father-in-law added that his family was worried about whether she (the daughter-in-law) would be able to conceive another baby when she could not bear a child for the next 10 months, as it was perceived as too long a birth spacing after the death of the third baby.

Parents have a passion to ensure their daughter's *Gharbar* because it is related to their daughters' marriage survival—and helps to prevent their daughter's detachment or divorce. They are influenced by everyone's concerns including relatives, neighbours and the adolescent girl's peers. One of the local stakeholders described the parents' concern for daughter's *Gharbar* as follows:

> *…unless there is a child [born], it is not considered a Gharbar. Parents become anxious about whether or not their daughters will give birth sooner. This culture puts pressure on young couples to give birth sooner. (Local Stakeholder, SH8)*

Gharbar in the context of high perinatal mortality

The context of uncertainties surrounding perinatal survival is related to the young women's *Gharbar*. Although the women and their families have a level of acceptance of perinatal deaths (Chapter Six), it is seen that after a loss, there is pressure on a woman from her parents' as well as the in-laws' family to conceive quickly. Like Bishnumaya, Birupa (Chapter Six, Box 6.3) also had that implicit fear related to *Gharbar*. In less than four years of her marriage, she gave birth to three babies; she lost babies in her first two pregnancies, and currently has a newborn boy.

It is seen that the perceived uncertainty of their babies' survival has not only led them to repeated childbearing, but has also postponed the rituals like *Chhaith*. Birupa's husband described the situation:

> *Last year, it was just a big expense during the Chhaith. The baby did not survive. We are not sure whether this baby will survive. We have also postponed Chhaith this time. (Birupa's Husband, a 21 year old father)*

During an informal chat with Birupa's husband, it was revealed that the couple had not used any contraception following their first pregnancy. Bearing babies repeatedly became a priority, like a norm until they had babies whom they felt confident of surviving.

For the sake of *Gharbar,* the young women are seen to have been caught in a vicious loop of child marriages leading to early and repeated childbearing and frequent baby losses. As discussed in Chapter Six, women like Penghmu (Box 7.1), and Yanghmu (Chapter Six, Box 6.14) were having to live with their parents after losing their babies. When Yanghmu lost her two babies, she felt she was being neglected in her in-laws' home and started living with her own parents, which, however, she perceived as her *Bhagya* (fate). Likewise, another participant, Sita (Chapter Six, Box 6.21) felt neglected by her husband after she did not have a baby surviving from two consecutive pregnancies. Implicit in all these women's stories is the uncertainty of babies' survival driving them to bear another child in the hope of it surviving, because having a surviving child strongly impacts on the survival of their marriage.

Gharbar related to gendered religio-cultural norms

The drive towards a girl's *Gharbar* is a result of gendered religio-cultural norms. It is believed that ensuring a daughter's Gharbar is good *Karma* that earns God's blessings *(Punya).* It is believed that if daughters are married *(Kanyadan)* before menstruation, it will bring more *Punya* to the parents. The parents who can see their great-grandchildren *(Panati)* are believed to be blessed with more *Punya* during their lifetime and reach heaven after death. One of the local journalists noted:

> *Child marriage is very common in this village. It is everywhere in this district. Here, people say if parents marry their daughters earlier (Kanyadan), before their menstruation, they will earn good Karma (Punya Dharma) and will be more blessed from Dewata (God). The earlier they have grandchildren, the more blessed they feel. (Local Journalist, SH9)*

There was a similar pressure for early childbearing from in-laws when they did not have grandchildren. An urge for grandchild is evident in Dilma's mother-in-law. Dilma (Chapter Six, Box 6.4) aged 21 had already lost her two newborn babies.

> *I have no grandchildren yet [she is sad and looks uncertain]. Dilma gave birth to a baby two years ago, but the baby didn't survive. And, last year another birth, but the baby didn't survive again. My younger son got married this year, but his wife is not yet pregnant. (Dilma's mother-in-law, a 61 year old woman)*

Motherhood is believed to ensure *Gharbar*. Marriage and birth of a baby are considered as a test of femininity *(Naritwa)* as well as masculinity *(Purushatwa)*. A local teacher described that early marriages were encouraged to secure these identities.

> *They want to have a baby as early as possible. Women feel that now they are mothers (Amma). Men feel that now they have proven their Masculinity (Purushatwa). (Local teacher, SH4)*

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To summarise, this section described cultural perceptions of early marriages and early childbirth perpetuating a vicious circle of vulnerability to poor perinatal survival. Daughters are considered ready for marriage after their first menstruation or earlier. Underlying this is their construction about settling a home for daughter *(Gharbar).* Such a construction has a powerful influence on families, urging them to defy or circumvent the law prohibiting child marriages. Marriage practices have changed from publicly celebrated marriages with parental consent *(Tike Bibaha)* to less public and often secret *Bhagi Bibaha*, thus still continuing child marriages. A range of gendered religious beliefs has driven young adolescent girls to early marriage and early and repeated childbearing. These beliefs included: the cultural belief about marriage of a daughter before menstruation as the parent's divine offer; belief that *Kanyadan* brings blessings to parents; belief that having grandchildren and great grandchildren opens the doors to heaven; and the perceptions about proving their masculinity *(Purushatwa)*, and femininity *(Naritwa)* earlier as the signs of their strengths.

7.1.2   Son Preference, Repeated Pregnancy and Perinatal Deaths

This section outlines how son preference is another key factor contributing to repeated pregnancies, and increasing vulnerability to poor perinatal survival in the villages.

The strong preference for sons over daughters has influenced many women to have repeated pregnancies with close spacing. Twenty five year old Hashakali (Chapter Six, Box 6.6) has two surviving daughters and one surviving boy, had two stillbirths and three abortions (two sex selective and one spontaneous). Currently, she is pregnant with her ninth child. She felt insecure with only one boy. It was evident that Hashakali experienced high-risk pregnancies, even with a prolapsed uterus in order to have additional boys.

> *We thought to have one more boy, and do the operation (Minilap—the female sterilisation method). But, now it seems that we couldn't have another boy yet. I have only daughters, not one more boy.*
>
> *… You know, I don't want to hide this. I have prolapsed uterus (Aangjhadne). If I carry any load of firewood or grass or any heavy thing, I feel it coming out, bulging out. It is burning and painful. I had this during this young daughter's birth. I suffered a lot while giving birth to this daughter. I suffered badly during the last birth [stillbirth]. (Hashakali, a 25 year old mother)*

Kanghmu (Chapter Six, Box 6.13) and Gobnajong (Chapter Six, Box 6.11) had similar experiences of repeated pregnancies to give birth to boys. With two (one newborn, and another post-neonatal infant) of her three boys dying, Kanghmu was living with her single boy. Due to the uncertainty of her only boy's survival, Kanghmu wanted to have one more boy. In five years of marriage, Kanghmu is currently five months' pregnant with the fourth child.

> *The first boy is with me. The second boy died two years ago, and another last year in May. The second child was one and half years old, and another baby died on the 11th day after birth. Had these boys survived, I would have already had operation [female sterilisation] in*

India [she used to stay in India before]. I didn't really like to have more babies, it is quite demanding, actually. I lost these two boys continuously, so I had to become pregnant again. (Kanghmu, a 25 year old mother)

It was noted that the participants also postponed the use of contraceptives until they had baby boys. Gobnajong has three daughters; she lost two boys. In the desire for a son, the couple has not used any contraception. Her husband explained:

We have only girls. I was expecting a boy from her, but it is not yet possible. My wife is also not using any contraceptive [Suhi: injection medroxyprogesterone] for this purpose. (Gobnajong's husband, a 37 year old father)

The uncertainty of the survival of babies particularly that of boys, has shaped the participants' contraceptive behaviour. Chapter Six described that having a vasectomy was considered to be against God's will. It was also noted that participants' unwillingness to use contraceptives, including vasectomy, was mainly related to the perception of uncertainty of their baby boys' survival. They preferred to postpone contraceptive use until they felt confident about their babies' survival, which could be confirmed when their children began to walk a few steps. Junamati described this situation:

The elder sister-in-law is using contraceptives [Suhi: injection medroxyprogesterone]. The younger sister-in-law and I still have young boys. We will do it once they grow up [to about 4 years old]. (Junamati, a 25 year old mother)

Junamati is a 25 years old illiterate woman from a lower caste. She was married at 11. She has two girls and two boys, and lost a baby girl last year. **[Box 7.4]**

Son preference is a deeply rooted gendered construction contributing to repeated pregnancies and increased perinatal deaths. This has widespread ramifications ranging from sex detection and termination of a pregnancy if the foetus is a girl, neglecting a baby girl and a woman. A local female activist narrated the story of a village woman who had 12 pregnancies in the hope of a baby boy. The woman lost four baby girls.

She gave birth to 12 girls. This time, I went to see her and found that she is pregnant with her 12th child. Of the total, her eight girls survived and four died. I told her, 'why do you continue giving births these many times?'. She replied, 'Madam, we are afraid of breaking our family succession (Aputo). We went to a faith healer, worshipped Dewata (God), and changed our house. However, still this is it Madam. What to do, I didn't have a boy yet'. (A woman activist from the local Women Development Office)

A local hospital nurse described a woman being harassed by her husband when she had not given birth to a boy.

She came to hospital alone walking six hours. No one had accompanied her. Before giving birth, the woman said to me, 'Sister, please, don't give me the baby if it is a girl child. Please tell me about the baby only if it is a boy'. This made me feel very sad. To her misfortune, she gave birth to a girl again. She became very sad and cried a lot. Moreover, you know, the woman said that her husband would not want her to come home if this was a girl this time. She said, 'if it is a boy, you bring it. Otherwise, kill that girl, and you would better die'. She was crying, couldn't embrace her newborn girl soon after birth. Then, we thought it is better

not to discharge her soon, and kept her in hospital for five days. She was crying at the time of discharge from the hospital. (Nurse from local hospital, HSP2)

Such a context has created a sense of fear among women when they have not given birth to a boy. The mothers, as well as newborn girls, are likely to be neglected and ignored after birth. I also heard from nurses that women and their visitors were reluctant to embrace and breastfeed their newborn girls. One of the nurses described an incident of a woman who had a shock when having a stillborn boy after repeated birth of girls.

I saw a woman had a shock after a stillborn boy. She had only girls before. Women are afraid of their husbands and families. I have frequently heard from women about their husbands neglecting them and abusing, 'if you don't give birth to a boy, I will get you out of my house'. (Senior Auxiliary Nurse, HCM1)

Couples without a son feel stigmatised in the villages and are called *Aputo/e* (almost infertile)*,* which is considered a stigma, and makes them feel sad. Such a context has led to couples accessing sex detection and sex selective abortions in pregnancy. Yasoda described:

You know, villagers make you feel down if you have only girls. My husband is bullied by his friends and neighbours for not having a boy yet. We need a boy. I have seen how others treat you when you have only daughters. This is embarrassing. I feel worried about it. In my last pregnancy, we went to Nepalgunj [a nearby city] to identify our baby's sex. It was a girl; we had to abort it. (Yasoda, a 25 year old mother)

Yasoda is a 25 year old social mobiliser. She was married at 16 and has a four year old girl. Both husband and wife are studying a Bachelor's degree. Yasoda lost her first baby at the 8th month of pregnancy. After her daughter, she lost a newborn on the 3rd day after birth, and aborted a girl this year. **[Box 7.5]**

Similar to Yasoda's story, not mothering a boy has led many other participants to detect their baby's sex in pregnancy, and terminate the pregnancy if the baby is a girl.

A nurse described the story of a local female community health volunteer who visited hospital during her pregnancy and requested identification of the baby's sex. After she was told by her doctor that sex detection was illegal, she attempted to induce an abortion using drugs from drug sellers and in a traditional way by drinking water mixed with ash (*Kharanipani*) which was locally believed to terminate a pregnancy. The nurse explained:

A few days back, one of our female community health volunteers asked me to identify her baby's sex. She was more than four months pregnant. She said, 'I took the anti-worm drug, water mixed with dried ash (Kharanipani) to abort the baby. Please sister, abort this baby, I already took some drugs from drug seller (private pharmacy)'. (Senior Auxiliary Nurse, HCM3)

It was identified that those who could afford to travel to the nearby city, Nepalgunj, went there to detect the sex of the foetus. Participants knew about a few private clinics in the city which illegally detect a baby's gender and do an abortion on request.

Couples, who are unable to afford to go to the city clinics, seek local faith healers to predict their baby's sex. If a faith healer predicts a girl, they buy drugs from local drug sellers and abort the pregnancy. It was identified that one of the participants, Punchamaya (Chapter Six, Box 6.19) attempted to terminate her pregnancy of over four months with some unspecified drugs from a local drug seller which however did not work. As a result, Punchamaya had to continue her pregnancy.

I took some drugs from a local drug seller to abort. But, it didn't help. After taking the drugs, my whole body was swollen. I felt pain all over my body, and became very weak. [She looks very sad]. (Punchamaya, a 35 year old mother)

Despite already having three boys, Punchamaya wanted to substitute her lost three babies with boys and therefore continued pregnancies. Currently, she is pregnant with her 10th child.

Son preference is rooted in the gendered cultural values of these villages, where it is believed that a son is a life-long carer, particularly during the parents' old age. More prominently, people of the *Khasan* community believe that a son is needed at the time of death of either parent and later to perform religious rites and rituals. It is believed that parents will not go to heaven if a son does not perform the funeral rites. A son is required to perform the Hindu rituals such as *Shraddha* (meaning to pay respect to the departed soul) and *Kaajkriya* (meaning rituals associated with paying respect to the departed soul) which are religious duties performed during the first 13 days of the mourning period. *Shraddha* is required to be performed annually by a son in the name of the deceased parents. A son is commonly preferred to a daughter in the *Lama* communities as well. However, the beliefs such as *Kaajkriya* and *Shraddha* are not prevalent among the *Lama* communities.

This section has described the gendered construct related to son preference and its consequences. Participants experienced repeated pregnancy, and frequent perinatal deaths. These events are related to gendered, religious and cultural norms favouring baby boys in the villages. They are driven by the parents' urgency and anxiety related to the settlement of their daughters *(Gharbar)* in their in-laws' homes. Participants in this study expressed a feeling of uncertainty about their babies' survival especially that of a baby boy. Such uncertainty has changed their contraceptive behaviour, making them unwilling to use, or postpone using contraceptives until they feel confident about ensuring the survival of their babies. The preference for sons has led them to sex selective abortions, and neglect of baby girls (not holding them close, delaying breastfeeding after birth). At the societal level, son preference is translated into neglect of older women and discrimination against mothers.

The next section explores the intra-familial power dynamics of being a woman, a daughter-in-law and a wife, and their pregnancy and birthing experiences.

7.2 Pregnancy and Childbirth in Intra-familial Dynamics of Relationships and Power

The villagers did not consider pregnancy and birth as special events needing additional care and support. Such consideration is related to intra-familial dynamics of relationships and power with respect to the unequal social position of being a woman in general, and a daughter-in-law in particular. A daughter-in-law has the lowest position in the family hierarchy and decision making (Luitel, 2001).

7.2.1 Work is the Priority: Pregnancy and Childbirth are not Special Events

Women are expected to work without a break during pregnancy as they would at any other time. Many families do not perceive that pregnancy needs additional care, rest, food and preparation for birth. Cropping and harvesting cereals are key duties allocated to women with no exemption even during their last weeks of pregnancy. During the fieldwork, women, especially daughters-in-law, were observed as always being on the move for day to day work related to collecting firewood, fodder and grass from the forest, grazing cattle and fetching water.

Plate 7.1 Women who went for firewood collection early morning, returning home at midday (at right, a postnatal mother)

Photo Credit: Author

Carrying out their daily work is more challenging for women in the villages due to the difficult terrain, often with steep paths up and down the mountains (Plate 7.1). As described in Chapter Four, villagers usually do their farming in two locations, at *Aulghar* (the low-lying area), and at *Lekhghar* (the high altitude area). These places are located at a walking distance of two to four

hours apart. Even during their last months of pregnancy, women frequently move from *Aulghar to Lekhghar* for work throughout the year. Such day to day work is a key priority in women's lives. I identified that it takes as long as three to six hours' walk to return home after collecting firewood, fodder (*Sotar)* or grass from the forest, which are routine jobs for women.

Many women return to their daily duties as early as the second week after giving birth. Plate 7.2 shows a picture of Bishnumati walking down to the *Aulghar* with a 14 day old newborn baby in her arms and a bamboo basket to resume her work. Bishnumati is a 31 year old woman who lost her two previous babies (one stillbirth and one neonatal death).

Plate 7.2 A second week's postnatal woman (Bishnumati) migrating with her family from *Lakeghar to Aulghar* **(walking on a steep mountain road with her 14 day-old baby on her arm)**

Photo Credit: Author

Indeed, there were many reports of women giving birth in the farmlands, or on their way to/from home in the forest. Birth preparedness, as discussed in the national policy strategies (Chapter Five) is a meaningless concept in the context of these villages.

> *You know, the baby sleeping there (she points inside a room) was born in paddy farm. I had labour pain in the farm while pulling weeds. (Punchamaya, a 35 year old mother)*

Devkumari (Chapter Six, Box 6.15) gave birth alone on the millet field. There was nobody to provide assistance, other than her cousin, who was ploughing the field a short distance from her.

> *I gave birth at the millet farm (Kodebari). I looked around to see if anyone was there. I saw my cousin at a distance, ploughing his farmland with oxen. I called out to him. I got a sickle (Baso) from him to cut the baby's cord, and I then made a thread from a piece of my shawl (Sal) to tie my baby's cord (Navi). When I had birthing pain, I thought to go back home and took a few steps, but the pain increased and I couldn't walk further. I gave birth on the farm. Later [after one hour], I wrapped the baby with my Sari and returned home. (Devkumari, a 27 year old mother)*

One of the participants narrated a story about a neighbour who gave birth in the field, became unconscious after giving birth and lost her newborn.

> *She had gone to the farmhouse (Lekha) to harvest potatoes. She was alone there. After birth, she became unconscious. No one was there to help. The baby was lying on the field, nobody to cut the baby's cord (Navi). Later, when she was conscious, the baby was already dead. (Penghmu, a 16 year old mother)*

Some women noted how the work exhaustion impacted their pregnancy. After frequent baby losses, Latima's husband perceived that she suffered from *Mojhlagne* (a disease of a woman's womb, Chapter Six). However, Latima (Chapter Six, Box 6.7) perceived that her exhaustion had affected the stillborn, the baby that died during the last month *(Hunemahina)* in her last pregnancy.

> *I had three falls during my last pregnancy. I think due to this Tapa (exhaustion) I lost my baby in the last month (Hunemahina). I had three falls [Repeats and nods her head]. (Latima, a 32 year old mother)*

Gobnajong (Chapter Six, Box 6.11) had a similar story of falling during her last pregnancy which ended up with a stillborn baby at the eighth month of her pregnancy.

> *I was chasing my cow, trying to return it to the farmhouse (Lekha). On the way, the cow ran away and entered our local river, crossed the river. …Water current in the river was strong. I couldn't move further, tried to get my feet firm on a stone in the middle of the river, but due to the water current I started shaking. The stone tilted and I fell into the river. I was badly hurt. I became sick for one month. Then I gave birth, the baby was dead, looked thin and dry, and baby's cheek was swollen. (Gobnajong, a 34 year old mother)*

Similar stories were heard from local health workers describing women's falls and pregnancy loss.

> *She was in the last trimester. She had gone to bring fodder in the forest. She slipped on the road, hurt her abdomen. She had bleeding and fainted. …Fortunately, the mother survived; however, the baby died. We didn't expect the baby to survive anyway. (Local Health Worker, HSP7)*

It was noted that the heavy workload impacted not only on the illiterate village women, but also the more educated female community health workers. An auxiliary nurse described her perinatal loss due to heavy work. She slipped and fell on the road while carrying a heavy jar of water. This resulted in her pregnancy ending in a foetal death last year.

> *I think loss of babies in pregnancy is due to carrying heavy loads. I was working in a community-based project. If I am doing only my office work, family members and the sister-in-law start complaining about me. They want me to do the work before and after my office time. One day, I slipped on the road when I was coming home with a jar of 10 litres on my back [with a strap across the head] and two jugs of five litres each in my hands. I fell on the ground. My belly bumped against the ground, and I started rolling down on the road. I had profuse bleeding after, and then delivered the babies. These were twin babies, both dead. I think it is the heavy load and the fall that hurt my pregnancy. (Auxiliary Nurse at a district meeting)*

7.2.2   Daughter-in-law: A Low Voice and Marginalised Member of the Family

Mother-in-law and daughter-in-law: ruler versus ruled

As described in the section (7.2.1) above, a married village woman suffers on two counts: as a woman and as a daughter-in-law. A woman's jobs become further pronounced when she is a daughter-in-law. A majority of woman participants in this study were living in extended families, two-generation families, a common tradition across Nepal. In the study villages, a daughter-in-law has the lowest position and little voice within the family. She is expected to obey her mother-in-law, including decisions made about her own and her baby's health.

Mothers-in-law do not perceive pregnancy and childbirth as precious events requiring special care and attention. Therefore, daughters-in-law are not supposed to expect special care and support from their in-laws' families. Hashamati explained:

> *No one tells you to have a rest, and no one brings any special food to eat. It is unusual if you talk about rest here. Mothers-in-law tell that they also worked and gave birth to their boys and girls. They ask you, ' are you the only woman giving birth? We also gave birth'. Who cares that you need a rest, you need good food? All that is expected from a daughter-in-law is work, work and work. (Hashamati, a 25 year old mother)*

Hashamati is a 25 year old illiterate woman living with her three baby boys and husband. She was married at 17. Her husband studied up to grade 12. Hashamati had already had one abortion and a stillbirth a year ago. **[Box 7.6]**

The daily work burden of a daughter-in-law also affects her breastfeeding practice. A nurse described the situation as follows:

> *They are always busy at work, leave their babies at home with in-laws and go to their farms and the forest. They can't even breastfeed a newborn on demand. When we advise them to breastfeed the baby on demand, they say, 'who is then going to help our work at farm? Who will help us to collect fodder and firewood?' 'Have you ever seen our workload at home, can you help that anyway?'. In fact, they are controlled by their mothers-in-law. (Auxiliary Nurse from hospital, (HSP2)*

As mentioned earlier, in the social context of these villages, a daughter-in-law has the lowest position in the family hierarchy. She has no authority and decision making power over her own health and reproduction. In addition to work expectations, there is a pressure for early and repeated child bearing as discussed above (Section 7.1.1).

Many participants reported the controlling nature of mothers-in-law. Referring to his own family situation, a local teacher stated that a daughter-in-law is so oppressed within her family that she is not seen or heard from, even when she is ill.

> *Our family system is autocratic. The elders, particularly mothers-in-law control everything. Daughters-in-law are considered as the lowest class persons. They are just the labourers within a family. Even when a daughter-in-law is pregnant, she has to cope with mother-in-law's regular complaints, and has to continue heavy work despite her illness. When she tells*

about her illness, the mother-in-law often does not trust her. Mothers-in-law think that she is telling a lie (Nauragareko) about her sickness. Why can't they consider their daughter-in-law as their daughter? She is their son's life partner [he becomes sad about it]. (Local teacher, SH4)

An activist belonging to a local non-governmental organisation raised a similar concern. He confirmed that mothers-in-law possess an unfair attitude towards their daughters-in-law, even during pregnancy, birth and after birth.

She wants her daughter-in-law to go through the same fate that she went through when she was a daughter-in-law. There is no one to support a daughter-in-law in a family. The day to day chaotic work in a family neither allows her to have a meal in time, nor let her have a little rest. We [the employees] allow our wives to have two months' rest after birth. Here, they (village women) don't have even two days of rest after birth. (A stakeholder from an INGO, SH1)

A daughter-in-law in the villages can hardly challenge such an oppressive situation. Some *Lama* families are a little more caring towards their daughters-in-law, at least immediately after birth. Yet, for a daughter-in-law, work is a customary norm, a key priority up to the last minute before birth. Gobnajong gave birth in the farmhouse (*Lekhghar*) while she was working and lost her baby during birth. Her mother-in-law stated:

I told my daughter-in-law not to go to the farmhouse (Lekhghar). I told her, repeatedly. I asked her, 'how do you care if you deliver your baby there? Both my daughter-in-law and my son didn't agree to stay here. They went to the farmhouse. On the fifth day after birth, she came back. I asked her what had happened. Then the son replied, 'she gave birth to a baby girl, she died during birth'. (Gobnajong's mother-in-law, a 58 year old woman)

Men's involvement

Husbands are not involved in matters related to the care of their wives during pregnancy and birth, and these are considered as women-only matters. Unless it is an emergency, men are not expected to engage in any of their wives' work or provide them with any support during pregnancy and birth. This is evident in Deviram's uncle's description of his daughter-in-law's childbirth.

My wife said, 'You men can go out. Daughter-in-law is in labour pain (Kaitha). Even we women can't really do anything here. What can husbands (Lognes) do in a woman's birth? (Deviram's uncle, a 46 year old man)

Deviram is a 25 years old illiterate man. He is a daily labourer. His wife aged 18 died this year on the 18th day after childbirth. Deviram lives with his 65 years old mother and two children: one three years old, and the youngest 35 days old on the day of this interview. Deviram's uncle is an office assistant in a local government office. **[Box 7.7]**

Women usually give birth alone at home with no support from their husbands. Punchamaya felt proud of herself and did not expect any support from her husband when she was giving birth alone.

…when I gave birth this daughter [the youngest one], I was alone. He [husband] doesn't know anything. I did everything: cord cutting, bathing, and washing all by myself. (Punchamaya, a 35 year old mother)

Similarly, although Saradevi was at home only with her husband when she had birthing pains throughout the day, she did not tell him about her labour pain. Rather, she gave birth alone in the *Gotha*. Unfortunately, she became unconscious after the birth, could not cut her baby's cord, and her baby had already died on the rice straw in *Gotha* when she regained consciousness.

> *My husband was sleeping. There were no other people at home. I had pain from the morning and delivered the baby in the evening. After the pain became severe, I went inside Gotha. I became very weak and unconscious after giving birth. When I woke up, my baby was lying dead on the rice straw [only then the husband noted that she gave birth].*
> *(Saradevi, an 18 year old mother)*

Saradevi is a young18 year old girl who lost a newborn baby last year. She is barely literate, went to grade two in school, and married at 13. This year, she gave birth to a baby boy again. **[Box 7.8]**

During the fieldwork for the current study, I did not see a single man accompanying their wives for antenatal visits or childbirths to the health facilities. Husbands are not expected to stay with their wives during birth in the health facilities. At home deliveries, husbands are not allowed to see their wives giving birth. Some women said that their husbands left home upon commencement of labour pains and returned only after the baby was born. Husbands can see their wives and babies once they enter home after the pollution days are over (discussed in Section 7.3).

Some husbands wish to support their wives, but cannot negotiate it within their families. They are afraid of becoming a bad son in their mothers' eyes. After the loss of their newborn baby last year, Fuladevi's husband wished to support his wife at work. However, he could not help her as this was considered to be against his parents' will, especially the will of the mother.

> *I can't tell her to have a rest. It is up to my parents, my mother. I don't like her to do heavy work. However, I can't really help. It is my mother who tells who does what in our family.*
> *(Fuladevi's husband, a 19 year old father)*

Fuladevi is an 18 year old girl, lower caste, *Khasan*, studied to grade nine and married at 14. Fuladevi is currently in the last month of pregnancy. Last year, she lost her baby boy on the 15th day after birth while in *Gotha*. Fuladevi's husband studied up to Grade Six, and is a cowherd. **[Box 7.9]**

A man is considered weak if he provides any physical and emotional support to his wife. In a post interview chat, it was evident that Fuladevi's husband felt that he would be mocked by his neighbours and other men in the village if he listened to his wife, and supported her in her everyday work.

Chapter Four described men working as daily labourers in carpentry, building construction, and in market shops. Some also go to India to earn as labourers. Assisting their wives in bringing firewood, *Sotar* (dry fallen leaves) from the forest is considered unacceptable for men as it is considered a woman's job. A local nurse confirmed this notion:

These are women working throughout the day. They work on the farm, go to the forest, and do household work such as cooking and fetching water. If a husband supports his wife, others tease him. Not only men, women themselves make fun of him. He is called a weak man, a man controlled by his wife (Joitingre). This is the culture here. (A Nurse from local Hospital, HSP1)

Another participant, Jasikala's husband, also raised his concern with regards to his wife's care during and after pregnancy as being non-negotiable in the family context. He negatively commented on how his family members did not permit his wife to have extra rest during her pregnancy. He added that his wife became a victim of a work competition among daughters-in-law and his brothers, to be called a 'good daughter-in-law' in his mother's eyes.

> *My wife can't have nutritious food and additional rest. You know these are brothers and sisters-in-law competing for work to become a good daughter-in-law or a good son. How can I expect here good food and a little rest for my wife? During her next pregnancy (third pregnancy), I am rather feeling like leaving this home. I want to go to a city with her, will work whatever is available, in hotel or as a labourer, and help my wife. At least, my wife can go to hospital there, can have a rest and good food. We lost two babies here. (Jasikala's husband, a 20 year old father)*

> **Jasikala** is a 19 year old girl, illiterate, *Khasan* and married at 16. She lost her newborn babies twice immediately after birth. Her husband studied to grade 10, and currently is the owner of a small tea and grocery shop in the village. **[Box 7.10]**

Some women interviewed in this study felt neglected by their husbands. Dhanasila (Chapter Six, Box 6.18) lost a baby at seven months of pregnancy last year. She lives with her four children. There was no one to help her when she experienced lower abdominal pain for nearly three weeks. Later, it was found out that her baby had died in the womb. Only her parents came to see her twice after birth. Her husband married another woman while she was pregnant and started living separately with his second wife in a house at a distance of ten minutes' walk. He did not come to see her once when she had to go through the pain of having a dead baby in her womb for three weeks.

> *He didn't come to see me once, neither during pregnancy nor after birth. I had lower abdominal pain for three weeks before delivering the baby [The baby had already died in the womb]. He did not come [tears]. My parents came twice. But, he didn't show up. (Dhanasila, a 39 year old mother)*

The stories of other (female) participants such as Penghmu, Sita and Yanghmo also provide evidence of similar neglect and abuse from their husbands. After being neglected and verbally abused by her husband and mother-in-law, Penghmu has been living with her mother.

> *It is very sad. Neither my husband nor my mother-in-law treats me well. My husband abused me. He frequently shouted at me, and beat me. I don't feel safe to go there. I am staying with my mother. I don't know when I can return to my in-law's home. (Penghmu, a 16 year old mother)*

Penghmu and Yanghmo were neglected by their husbands and in-laws due to baby losses. After loss of her two babies, Yanghmo felt neglected by her husband and mother-in-law, and moved to her parents' house. For another participant, Sita, the abuse was related to her husband's drinking habit. Sita was physically beaten by her drunk husband during her previous pregnancy. She is experiencing neglect during the current pregnancy as well. Sita had already had a miscarriage and a neonatal death. It is seen that Yanghmo and Sita are coping with the neglect by accepting it as their *Bhagya* (fate).

To sum up, due to gender structure and family hierarchy, work is the top priority for women within the family, with little care and attention to their pregnancy and childbirth. The use of family planning methods is still far from reality and neither pregnancy nor childbirth is considered as a special event in the women's lives. Women may end up giving birth anywhere, such as on the way to work, in the forest or the farmland. Household work, farm related work such as cropping and harvesting, and everyday work of bringing fodder, grass and firewood are considered to be women's duties without exception, even during the last stages of pregnancy. The heavy workload does not even allow women to breastfeed their babies on demand. The work burden of a daughter-in-law is related to the gendered dynamics of relationships and power within a family where the mother-in-law is the dominant controller. A daughter-in-law lacks voice and is marginalised within her in-law's family, holds the lowest status and is often treated as (unpaid) labour. Husbands are rarely involved in matters related to pregnancy and birth. A few men, despite their willingness to help their wives, are not able to negotiate support for their wives during pregnancy because of their gendered position. Some men were rather indifferent and neglected their wives after baby losses. Such a context has been a driving factor for women's experience of repeated baby losses in the villages.

7.3 Perception of Childbirth as a Polluted Event: Birth in *Gotha* (cowshed), and Giving Birth Alone

The periods around childbirth and during the first three weeks after birth are believed to be polluted periods (locally called *Juthosutka*). Local communities avoid doing certain things during this period for example worshiping their *Dewata* (God), and observing festivals and rituals. Such perception of 'pollution' leads to unsafe birthing practices such as giving birth in *Gotha* (cowshed). While the government's health policy supports health facility births and the use of skilled birth attendants, giving birth in the *Gotha* is a culturally accepted practice to keep the perceived pollution away from home.

In the study villages, a birthing woman is traditionally considered untouchable *(Chhuhi)* and left to give birth unaided. Attendants, including family members, feel hesitant to touch her. Those who have stronger belief in *Dewata* (God) are even more afraid to touch a birthing woman including her baby. Jasikala (Box 7.9) who lost two babies soon after birth, described:

Both times, I gave birth alone [in Gotha]. During the first time, my sister-in-law witnessed, but she didn't touch me. She is a faith healer (Dhami); she worships Dewata (God). I gave birth alone and buried the placenta myself. This time, there were my father's sister (Fupu) and my mother, but neither of them could touch me. I cut the baby's cord, and buried the placenta myself. (Jasikala, a 19 year old mother)

Women and their families feel safe giving birth in the *Gotha* which helps to keep the birthing woman and baby untouched by others and prevents polluting the home and their *Dewata* (God). *Gotha* refers to the ground floor of a house (Plate 7.3) where the family keeps cattle, goats, sheep and chicken. If the *Gotha* has any spare space, they also store firewood, grass and fodder. Women give birth in a corner of the *Gotha*, usually at a little distance from the cattle. Some houses also have a separate room on the ground floor, in which they normally store grass and firewood for the rainy season. It has normally only one entrance, little ventilation, and often no doors. The floor is usually damp and rough; women give birth on old and worn-out dirty rugs, or they use some dry straw on the floor. Confinement of mother and baby in *Gotha* during birth and immediately after birth increases the chances of exposure to various infections and consequent ill-health.

Plate 7.3 *Gotha* (Cowshed), birthing place of women in the villages

Photo Credit: Author

As a birthing place and mother and baby's confinement during the most critical time of birth and immediate postnatal days, the *Gotha* makes both mother and baby vulnerable to ill health, poor attention and low care.

The perception of birth as a polluted event is so strong that despite being deaf and mute, Latima had no exception but to stay in *Gotha* for 16 days. Latima (Chapter Six, Box 6.7) went through ten pregnancies, and lost seven babies. Her husband got permission from his mother to sleep in *Gotha*

and make his deaf and mute wife alert to breastfeed the baby. As he outlined, he did not even touch his wife and the baby. Instead, when the baby cried, he awoke his wife by poking her with a wooden stick and a small stone so that she could breastfeed the baby.

> Because my wife [Latima] can't hear and speak well, my mother also stayed in Gotha to look after the baby. My mother stayed in Gotha with my wife during all births except the last one. Last time, it was my turn because my mother got sick. I stayed in Gotha, slept at a little distance from her. Though I couldn't touch her, I had to be watchful and see if the baby was all right. I poked at her with a small stick, sometimes a little stone whenever I heard the baby crying, or saw the baby waking up from sleep. I woke her [Latima] to breastfeed the baby. [Latima smiles at him when he explains to her with sign language and tells her about his days in Gotha.] (Latima's Husband, a 39 year old father)

The idea of pollution meant childbirth does not require a clean birth place. A local health service provider also reaffirmed the villagers' perception of birthing as a polluted event.

> They don't select a clean place for birth. It is usually outside the home, in front of the Gotha, or on the side of the Gotha. First, they think of avoiding Jutho (the pollution), because by birth it is considered that a woman is making the home polluted. They are concerned not to make their Dewata (God) unhappy. (Auxiliary Health Worker, HSP7)

With these beliefs in mind, it is perceived that God will be unhappy and will curse the family if a woman gives birth inside the house, or enters the house before the day declared auspicious by a local priest or pundit. During this confinement in *Gotha*, other family members have very little contact with the mother and baby. Shivakumari's (Chapter Six, Box 6.12) baby died on the seventh day in the *Gotha*. Her mother-in-law was hesitant to enter *Gotha* to assist Shivakumari when her labour started. Instead, the mother-in-law sent her young 14 year old daughter to watch the birth and to ask if she needed any assistance. The mother-in-law did not even see her grandchild as the baby died in *Gotha*. Shivakumari's mother-in-law stated:

> We have God (Dewata) inside our house. It is not good to see and touch a birthing woman. When my daughter-in-law started her labour, I was inside this house, over there [she points a place near kitchen]. Daughter-in-law went inside the Gotha. My younger daughter [14 year old] also went to see her inside the Gotha.
>
> ...I don't know how that baby died. I didn't go to Gotha. I was waiting to see the baby once my daughter-in-law entered the home. (Shivakumari's mother-in-law, a 53 year old woman)

Attendance at birth by someone as a mere witness was also evident in the case of Devkumari and her sister-in-law's childbirth experience. During their childbirths, the mother-in-law went inside the *Gotha*, but she was only a witness, staying at a little distance from the birthing women.

> For both of my daughters-in-law, I helped them during birth. I stayed close, [but did not touched them] and told them to cut and tie the babies' cord [she verbally described the procedure to cut and tie baby's cord from a short distance]. (Devkumari's mother-in-law, a 67 year old woman)

Women are expected to be brave and courageous and give birth unaided and isolated. They are encouraged to hide their pain, remain quiet during labour, and not to let others hear or notice the labour pain or the event of birth. *Gotha* is an ideal place to keep the mothers isolated from others.

This isolation is also considered appropriate to prevent witchcraft or evil eyes *(Boxi or Ka/optini)*, which is believed to afflict the birthing woman and her baby.

Even if a traditional birth attendant *(Sodeni)* is present at the birth, the women prefer to give birth on their own without support.

> *My wife is a traditional birth attendant (Sodeni). We are the closest neighbour and relative to help them (Deviram's wife). However, she gave birth herself. No one had to use hands during birth [she was strong]. She gave birth herself. (Deviram's uncle, a 46 year old man)*

Unfortunately, Deviram's wife died due to bleeding on the 18th day after birth. On the day of this interview, the baby was 35 days old and cared for by his grandmother.

Such a perception about pollution has affected the birthing women to such an extent that they did not receive support, even in high-risk situations. A local auxiliary nurse described her experience in the village when she saw a woman giving birth on the way and bleeding, and others watching from a distance.

> *During my field visit in the village, I saw a woman who delivered her baby on her way to the birthing centre. She was bleeding. There were other women, but they were all just watching her from a little distance. I hadn't had gloves that time. I used polythene bags as gloves. I removed her placenta. The birthing centre was still an hour away. We then made a stretcher out of a shawl (Sal) and requested them to carry her to the birthing centre. (Senior Auxiliary Nurse, HCM3)*

The nurse added that during the pollution period *(Chhuhi)*, some families do not wish to touch the baby even after its death; the mother has to bury the deceased baby on her own.

It was identified that providing childbirth services is not preferred by some health volunteers and support staff. Some local female community health volunteers feel hesitant about touching birthing women due to their faith in *Dewata* (God). I met a male support staff member in a local health facility who said that he was afraid of pollution while being around and touching a woman in labour in his previous work at hospital.

There are some cultural differences between the two communities under study. Perception of birth pollution is found to be less prominent among the *Lama* women. The *Lama* women gave birth in *Gotha*, also called *'Raikosa',* but they did not stay there as the *Khasan* women did. They entered the house immediately after birth and stayed at the side or in a separate room without polluting the kitchen area and the place where they worship *Dewata* (God). Dolma's husband explained:

> *We didn't put her (his wife) in Gotha. She went to Gotha just to give birth. She came up here [inside the house, on the first floor] immediately after birth. She was forbidden to go to the kitchen area and to the worshipping place inside house. She stayed over there [the place inside the home on a side] in that corner for seven days. After this, the pollution (Chhuhi) was over. (Dolma's husband, a 35 year old man)*

Dolma is a 25 year old woman from the *Lama* community. She was married at the age of 22. Dolma lost her first newborn on the day of birth last year. Currently she is pregnant. Her husband is a local farmer. He had married two women before Dolma. Both of them died due to illness. **[Box 7.11].**

In the *Khasan* community, people are condemned if they do not abide by the rules of pollution days. Binita (Box 7.2) entered the house after five days in *Gotha* when her husband told her not to stay additional days in *Gotha*. However, their neighbours blamed them for violating the idea of ritual pollution. The couple were blamed for their two losses, claiming these were due to not obeying the pollution ritual for at least three weeks. During the first birth, the baby was stillborn at the seventh month of pregnancy, and the second time, it was a sick newborn admitted to the local hospital who died while under treatment. After this, during the third time, his wife continued for three weeks of *Gotha*, thus fully obeying the pollution days. She has an eight months old surviving baby boy, and is already pregnant with her fourth child.

In some families, women are allowed to enter the home earlier if the newborn dies in *Gotha*, and if they have a separate room to stay, as seen in Shivakumari's case (Chapter Six, Box 6.12). I explored the fact that the number of pollution days varied between a newborn girl and a boy. A woman who gave birth to a baby boy was considered less polluted, and entered home as early as on the sixth day to perform *Chhaith.* However, the pollution period for a newborn girl *(Chhoriko Chhuhi)* was longer. The celebration only occurs for a newborn boy on the sixth day after birth which is believed to bring good luck to the baby. The naming ceremony is also held only for the boys, varying in time between nine to eleven days after birth.

Observing the pollution belief during menstruation and birth is considered a woman's religious ritual *(Dharma)* by the faith healers. Faith healers strictly avoid touching a woman and her baby during and after birth. They sprinkle rice grains and do *Mantra* on the woman from a distance. They remain careful not to physically touch the woman and her baby in order to prevent them from being polluted. As a local faith healer described:

> *When a woman is giving birth, I sprinkle rice grains and do Mantra (Paturne) from a*
> *distance. I immediately leave the birthing place after the baby comes out, that is pollution*
> *(Chhuhi). I can't touch the mother and baby. I can touch them only after the pollution [period]*
> *is over.*

The study found that the concept of 'pollution' during menstruation and birth is very strong as any movements and critics against the practice are rejected by the communities.

> *…some people are criticising Dewata (God). The former and today's God, this can't be*
> *different. This previous Dharma (religious ritual) and today's Dharma shouldn't be different.*
> *How can we protect the Dharma if a woman enters home after birth? I think it has created*
> *many problems due to not following this Dharma. Staying separately during pollution during*
> *both menstruation and birth is from ancient time. Our ancestors followed it. This culture is*
> *not introduced by the political parties [Refers to the Maoist revolution and their criticisms*

about the pollution]. What are they going to achieve by talking against this culture? (Local Traditional Healer, TH2)

Size and Basic Amenities in the House as a Factor in Negotiating Birth Pollution

Besides the gendered religious notion of considering a woman impure during and after birth, the small size of the houses, particularly in the *Khasan* community, appears to perpetuate pollution associated with childbirth. Houses in the *Khasan* community have limited space that cannot accommodate a woman during menstruation and after birth. These are small sized mud and stone houses shared by the family members and cattle including storage of grass, firewood and *Dewata* (God) inside their house. The ground floor is used for cattle, and the first floor as the living space (Plate 7.4) for the family. Many houses have only one bedroom (*Buigal*), used mainly by in-laws/parents. The kitchen hearth is usually situated at the centre, and *Gadhi* (symbol of their God) in a corner behind the kitchen. Family members other than parents sleep on the floor around the kitchen. During menstruation and birth, women rarely have any space on the first floor and stay at a side in the *Gotha*, on the ground floor.

Plate 7.4 *Gotha*—the ground floor for cattle and women during birth, and the first floor for the family Photo Credit: Author
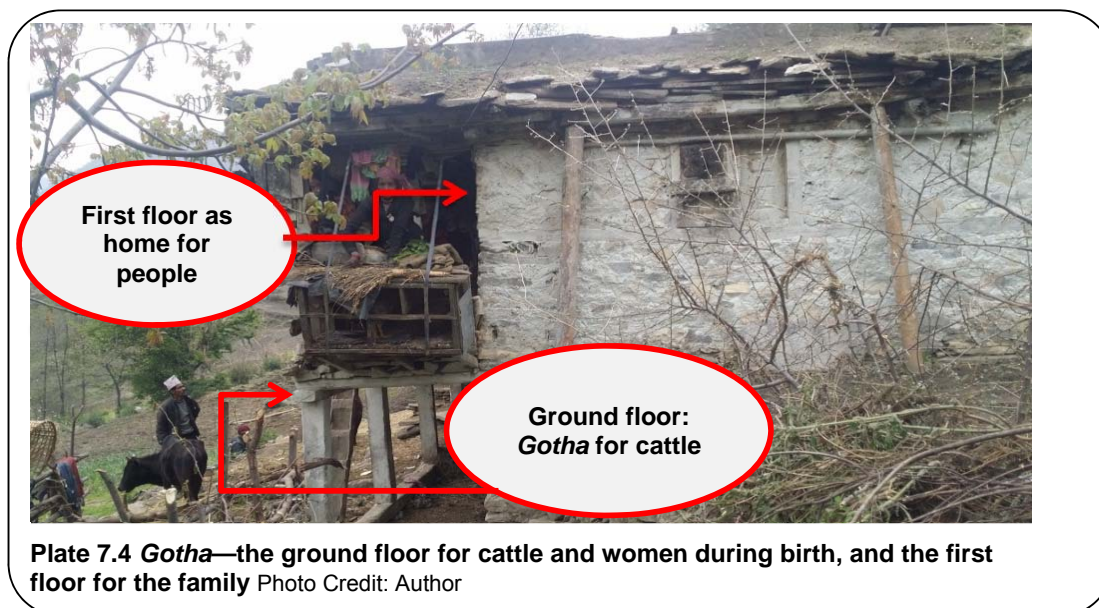
In the *Lama* community, houses are usually larger with separate rooms. The larger space allows women during menstruation and/or birth, to stay in the home on the first floor, usually in a separate room.

In the *Khasan* community, some families have very small houses where the *Gotha* is too small to accommodate women who have given birth. For Rupamati (Chapter Six, Box 6.16), it became very difficult to stay in the *Gotha* due to its limited space. Instead, she went to the wooden hut of her aunt's house. Rupamati stated:

> *I stayed for five days in my Gotha. It is very difficult here, no space due to our cattle, firewood and chicken. After five days, I requested Punchamaya [her aunt]. She provided a roof top wooden hut (Paand). Then, for rest of the days, I stayed there. (Rupamati, a 20 year old mother)*

The roof top wooden hut (*Paand*) had direct access, and did not require anyone to get there via her aunt's home (the first floor with *Dewata* and kitchen). Rupamati stayed in the wooden hut for 19 days until her pollution period was considered to be over. Unfortunately, her baby became sick and died on the 20th day after birth which she perceived as *Banlagne,* an unknown bow attack, which is believed can only be cured by experienced herbalists *(Baiji)* and worship of God (Chapter Six).

It was found during this research that one could negotiate finding a space in the household or outside that could be used for reducing the vulnerabilities of confinement in *Gotha* (cowshed). When there was no separate room available to give birth in the house and there was no space even in the *Gotha*, Deviram's wife was taken to a local community birthing centre *(Bhavanghar),* where his uncle negotiated with the office assistant of the birthing centre to provide a room for Deviram's wife for up to the fifth day after birth. She gave birth to a boy, and was allowed by Deviram and his uncle to enter a corner of the house on the sixth day after birth.

> *We took her to the community birthing centre (Bhavanghar). She was all right that day. She stayed there for five days. We could have brought her back home sooner, within two days [she had complained pain and bleeding]. However, we didn't because we have God (Dewata) in the house [Deviram's house]. We have a very powerful God (Khadar Dewata). Also, we did not have space inside Gotha. Though, I am living in a separate house. This is (Deviram's house) our main house from our ancestors. Therefore, she remained in the birthing centre for few days before coming to home. (Deviram's Uncle, a 46 year old man)*

In addition to the physical space, poor housing structure and the lack of basic amenities inside a house such as water supply and toilets have perpetuated the perceptions of birth pollution in the villages. The first floor, which the villagers used for family members, is not easy to access by a woman who has recently given birth in the *Gotha*, because one had to climb a steep wooden ladder to reach the first floor (Plate 7.5). The steep ladders are not easy to climb. The rungs of the ladders are too narrow for anyone to step on safely. I came to know of some incidents in the village where women in late pregnancy fell from the ladders and became sick. There were also incidents of baby deaths in pregnancy due to falls from the ladders. In addition, there are practical difficulties related to access to a toilet and water tap/well for the recently delivered women. If women are inside the house (the first floor), they frequently need to climb up and down the ladder to access the toilet, and to have daily baths and wash. The bathroom and toilet are rarely built inside the house, neither is there any water supply inside a house. Toilets and water taps are usually around 10 minutes' walk or even longer from the house. Living in *Gotha* (the ground floor) made it easier for the women to frequently access toilets and water taps.

Plate 7.5 Ladders used to access their home (the first floor) from *Gotha),* a last trimester pregnant mother climbing up (at right)

Photo Credit: Author

This section has described the participants' perception of birth as a polluted event. Abiding by norms to avoid pollution *(Chhuhi)* is considered as a religious duty *(Dharma)*. A woman and her baby are considered impure (untouchable); giving birth inside the house is considered to pollute the house and their *Dewata* (God). *Gotha*, is therefore, considered a culturally safe place for birth. The pollution days vary from one to three weeks, shorter when a boy is born (around a week), and shorter overall in the *Lama* community. Women have to deliver by themselves without even a lay birth attendant, let alone a skilled birth attendant. They are encouraged to deliver unaided and isolated to keep the labour private, and to supress their labour pain. Receiving any health care and postnatal follow-ups are rare experiences during the confinement. Therefore, this has increased vulnerability to poor perinatal survival during the most critical time of birth and the early postnatal period. Confinement in the *Gotha* is also influenced by the easier access of basic amenities such as water supply and toilets, which are located on the ground floor so that the women do not have to climb difficult (and unsafe) ladders if the basic amenities were located inside the house on the first floor.

7.4 Discussion

In this study, gendered constructions have emerged as major factors that perpetuate perinatal deaths in the mountain villages of Nepal. Women's experiences and perceptions revealed that their pregnancy, childbirth and postnatal care are complicated phenomena in the complex interrelated gendered constructions of girl settlement *(Gharbar),* weak position of a daughter-in-law within a family, and rituals about pollution from birth and the postnatal period.

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The first theme discusses gendered social constructs which make women and babies vulnerable to poor perinatal survival: child marriage, son preference and repeated childbearing. Child marriages and son preference are common in many developing countries and a range of studies describe a high prevalence of child marriages (Maharjan et al., 2012; Sharma et al., 2008) and son preference (Almond, Edlund, & Milligan, 2013; Arnold, Choe, & Roy, 1998; Barot, 2012; Brunson, 2010b; Pande et al., 2006) in South Asia as socio-cultural factors contributing to poor maternal and child survival. In discussing son preference, other studies have described sex selective abortions, neglect of women and girls, and discrimination through withholding care from newborn girls due to the son preference as common practice in South Asian countries (Arnold et al., 1998; Barot, 2012; Pande et al., 2006). This study identified that in the study villages similar beliefs and practices exist, but in addition the construct of *Gharbar* is a major driving factor which perpetuates a vicious cycle of early marriage, and early and repeated childbearing (often closely spaced) with the strong desire for a live baby boy (Figure. 7.2).

Figure 7.2 Vicious loop of repeated pregnancy and baby loss in the study villages
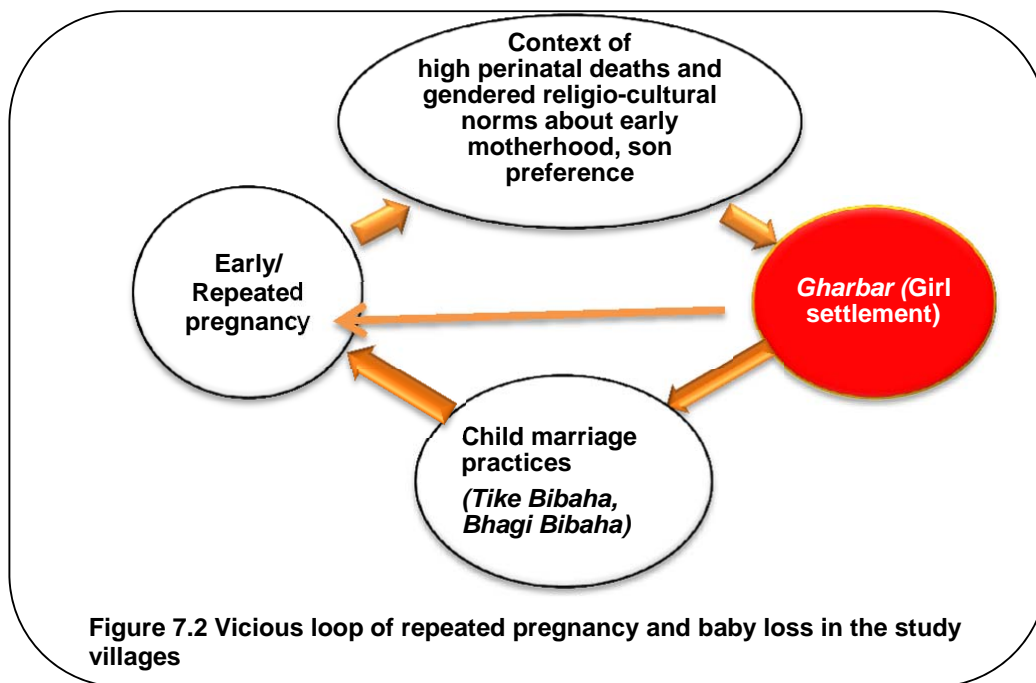
Source: Drawn by the author based on data analysis

Construction of girl settlement *(Gharbar)* in this study is consistent with the results of studies in India describing the socio-cultural context of marriage survival and having children (Patel, 2006; Riessman, 1995; Widge, 2002). Having a child (motherhood) is compulsory in Indian societies, which is seen as a factor enhancing the woman's status, and cementing the fragile bonds of marriages between spouses. Patel (2006) described that a childless woman feels anxious, has low self-esteem, becomes powerless and in most cases faces neglect and divorce. In this study, the drive towards girl settlement is also linked to similar pressures for early motherhood to bear babies at a young age, and pressures for immediate child bearing when a woman loses a baby and has

no baby boy. More than counting the babies' deaths, it is more about repeated childbearing in the hope of having a live baby, and thereby settling in a *Gharbar* to save marriage and feel secure in the family of the in-laws.

Likewise, the context of girl settlement in this study still resembles the description by Ware (1981) of the female life cycle of a typical woman in many traditional societies of developing countries. Ware described the adolescence stage as being considered important in the developing countries in regards to protecting virginity, entering the boy's family (early marriage) to contribute to agriculture and household duties, and to bear children earlier especially boys (sons) so that they feel secure in their present as well as later lives. Although Ware described it in terms of quality of women's reproductive life in general, this study adds that this is equally crucial if we are to address ongoing perinatal deaths in the study region.

Repeated childbearing is also related to the acceptance and fatalism surrounding perinatal deaths, as discussed in Chapter Six, Section 6.3. Deaths are of little concern to people in these villages, as they are rationalised to be the results of their *Karma*, fate or destiny. Giving repeated birth has been simply an option to secure chance of survival due to the high mortality context. It is not how many babies die, but how many survive, which is counted in the villages.

Gharbar and child marriages: It is evident that adolescent pregnancy bears a higher risk of adverse pregnancy outcomes, and has a 50% greater risk of stillbirths and neonatal deaths (Bhutta et al., 2014; WHO, 2007a). In many societies, including those of remote and mountainous Nepal, adolescent pregnancy is preceded by child marriage. Therefore, discussion of *Gharbar* that perpetuates child marriages, is an important topic in this study. The construct of *Gharbar* has been a key factor, powerful enough to make people defy any legislation against it, which has fuelled the continuation of child marriage practices. Child marriage has been illegal in Nepal since 1963 (Human Rights Watch, 2016). After the passing of the Children's Act in 1992, continuation of child marriages is considered as a criminal offence violating child rights. Age of marriage has shifted from early marriage contracts *(Tike Bibaha)* before adolescence to teenage marriage culture *(Bhagi Bibaha),* still continuing marriages below the minimum legal age at marriage. One of the serious concerns in *Bhagi Bibaha* is that none of these marriages is registered. Additionally, neither a baby born in such marriages, nor the death of a baby born in such marriages is registered officially until the mother reaches 20 years of age (legal age for marriage). *Bhagi Bibaha* has become a way to escape from the eyes of legal bodies. Registration of marriages, births and deaths before the mothers reach the legal minimum age of marriage is perceived as a threat to the continuation of *Bhagi Bibaha*. The poor registration of these vital events is to evade the detection of practices punishable by law.

Gharbar and son preference: The present study adds an insight into the deeply rooted belief about son preference that it is inextricably related to a girl settlement *(Gharbar).* It is perceived that

the birth of a son makes a woman's home, that now makes a woman (daughter-in-law) an insider to her in-laws' family. Birth of a baby boy positively impacts on a woman's marriage survival, makes a woman feel secure and raises her status within the in-law's family. Such a context is similar to what Ware (1981) described as giving birth to a son being the succession (immortality) of the extended family (the son/s). Extended family (living with a son and his family together) is like a government for parents in traditional societies and is extremely important particularly during old age because there are no old people's homes (residential homes) in many developing countries. A son is considered even more important when a woman loses her husband or gets divorced. Son preference also aligns with gendered norms and beliefs that having grand and great grandchildren, preferably baby boys sooner, is linked to the survival and prosperity of the parents. Sons are needed at funerals *(Kaajkriya)* and for performing annual rituals after their parents' death. It is also believed that a son is a ladder to the parents' afterlife peace and prosperity in heaven.

Studies describing son preference in south Asian countries (Arnold et al., 1998; Barot, 2012; Pande et al., 2006) have low focus on how son preference has impacted on poor perinatal outcomes: stillbirths and neonatal deaths in these countries. The present study adds that the tradition of *Gharbar* is an underlying motive behind repeated and closely spaced pregnancies to give birth to a son, often resulting in sex selective abortion of female foetuses to satisfy people's preference for sons, even though such abortion is illegal in Nepal (DoHS, 2016). The present study explored that in addition to rampant sex selective abortion, son preference has led to the neglect of baby girls (when they are born), and neglect and discrimination of women. Not only the mother of a newborn is not treated well, the newborn girl is also neglected by not embracing her or by delaying breastfeeding and other immediate care which are critical during these early periods. Loss of a newborn girl does not become a big concern when they do not yet have a boy. As discussed also in Chapter Six, the relatively easy acceptance of a stillborn girl or early death of a newborn girl is related to this attitude of son preference. This is especially highlighted in the present chapter with the story of a woman, who in the desire of having a baby boy, gave birth 12 times and lost four newborn girls, but these losses were not considered worth remembering.

Sex-selective abortion: This study argues that in the study villages, son preference is a crucial factor in perinatal survival, especially when sex-selective abortion is resorted to, as mentioned above to ensure the birth of a male child. As far as I know, there was no evidence of infanticide in the study villages. In the study villages, the conception of a female child in successive pregnancies is considered unwanted, therefore; such a pregnancy (with a female foetus) is terminated. Lanata (2001) states that the neglect of a female child is a factor related to children's malnutrition and an increased mortality from respiratory and diarrhoeal diseases. A form of neglect is also evident in the study communities when a girl is born in a successive pregnancy that was not terminated before birth. It is identified from the present study that if a girl is born, she is not embraced after birth, the length of confinement (pollution period) is longer, breast-feeding is postponed (Chapter

Eight), and also that the mothers are discriminated against, all of which adversely affects their settlement at in-laws' home (*Gharbar)*. It is also acknowledged that sex selective abortions to maximise the chances of having surviving male children contributes to poor perinatal survival, particularly in the case of closely spaced pregnancies, which have female foetuses or produce female children. With a strong desire to give birth to a male child, participants used traditional and modern abortifacients to abort a pregnancy that carried a female foetus. It was found that participants, who could afford to pay for their travel, accommodation and the expense in private clinics in a city nearby, opted for abortion when the baby in the womb was identified as female. However, those who could not afford to pay for sex detection and abortion in private clinics, resorted to faith healers to randomly predict their unborn baby's sex by the healers. Such parents were reported to practise traditional abortion practices such as drinking ash mixed with water *(Kharanipani),* and visiting local health facilities and drug stores to use anti-worm medicines such as Albendazole. Any more detailed discussion around the use of foeticides is beyond the scope of my study.

The second theme emerging out of this study pertains to pregnancy and childbirth in the intra-familial dynamics of relationships and power. In this study, the intra-familial gendered role construction is particularly responsible for not seeing pregnancy and birth as special events worthy of providing additional care. Firstly, these are viewed as a woman's only duty, which should require no special exemption from work—even heavy physical work, and secondly, a daughter in-law is at a double disadvantage (a woman suffering from another woman) due to the negative controlling role of the mother-in-law, often preventing access to even basic health care. All of these make the young girls and their babies vulnerable to sickness and deaths. The policies (see Chapter Five) discussing birth preparedness have been practically non-existent in such a context. It is noted that besides changing the attitudes of mothers-in-law to be more supportive of their daughters-in-law, finding socially acceptable ways for the community to encourage men's interest and involvement in pregnancy and childbirth, should be a major priority towards improving maternal and perinatal health.

In many South Asian and African countries, mothers-in-law are the power bearers in families to decide access to health care (Hussein et al., 2012), and this was no different in this study. Previous studies from Nepal (Kaphle et al., 2013; Shrestha et al., 2012; Simkhada et al., 2010) described the crucial role of mothers-in-law in their daughters-in-law's pregnancy and childbirth. Kaphle et al. (2013) described mostly positive roles of mothers-in-law in care and support during pregnancy and birth. It appears that Kaphle et al. did not identify tension between daughters-in-law and mothers-in-law regarding accessing health care, as is found in this study. Similar to Simkhada et al. (2010) and Shrestha et al. (2012), the present study noted that mothers-in-law are often seen in negative controller roles, often imposing their own experiences of pregnancy and childbirth on their daughters-in-law, however difficult those experiences might have been. It may be that in these

communities, becoming a mother-in-law is the only chance a woman has to show her pride, and assert her status and power, and she does this also by reinforcing the status quo of how she has experienced her own pregnancies, births, and losses. At the same time, the prominent role of the mothers-in-law in maintaining this hierarchy is perhaps not surprising among women who themselves were never treated equal to men or anyone in their family until they became a mother-in-law.

More than 25 years ago, the International Conference on Population and Development of 1994 (ICPD 1994) recognised reproductive rights as rights to decide number, timing and spacing of children (UNFPA, 2014). One of the recommendations of the conference is that both men and women have access to information, health care, and family planning. The ICPD encourages mutually respectful and equitable gender relations, putting women's needs in the centre, and empowering women to enjoy reproductive rights. To ensure gender equality, men are expected to bear an equal share of domestic chores, family planning, prenatal, maternal and child health and in every sphere of public and private life. National policies (Chapter Five, Section 5.3) have also frequently cited the ICPD, acknowledging the importance of women's empowerment and reproductive rights to improve mother and child survival by increasing the uptake of quality maternal and childbirth services. In this regard, pregnancy and childbirth are recognised as special reproductive roles to be fulfilled in mutual partnership of both men and women. However, everyday household and agricultural duties have been the main priorities for the women in these villages under study, so much so that pregnancy and birth are not considered important at all. A daughter-in-law is viewed as someone who has to take the strong test of the local gendered expectations.

None of the previous studies from Nepal (Kaphle et al., 2013; Shrestha et al., 2012; Simkhada et al., 2010) has specifically discussed men's role in pregnancy and childbirth. In the present study, husbands were rarely involved in matters related to pregnancy and childbirth, even though national and international policies such as ICPD advise increasing male participation in reproductive health. It appears that these policies have hardly reached the men and women in the study areas. It is known that in many developed countries, men's engagement in pregnancy and childbirth has been enhanced through parents' group classes, and encouragement to stay together and support their partners during labour (WHO, 2007c). As evident in WHO (2007c), 95% of prospective fathers in England and 95% in Denmark in mid-1990s, were by the side of their wives during labour at the hospital. Developing countries, particularly their low socioeconomic areas, are far behind developed countries in terms of male participation in supporting their pregnant and postnatal wives. In the study villages, pregnancy and birth are strongly maintained as women's business, and men who wanted to help were dissuaded from doing so for fears of social stigmatisation. Men in the study villages are not expected to stay at home during a woman's childbirth; neither are they allowed to stay with their wives if they deliver at a health facility. Moreover, some men, along with their mothers, neglect their wives after birth if she has given birth to baby girls repeatedly. Men who

listen to their wives are not considered 'good sons' in the eyes of their mothers, and those providing care and support to their wives are often criticised in the communities as weak, or a womanly man *(Joitingre).* Therefore, gendered status of men has been a barrier to engage them from pregnancy and childbirth related matters.

On the other hand, in Asia and Africa in particular, men's involvement in maternal and child health should be considered crucial for reducing maternal and perinatal mortality by adopting family planning practices and increasing women's access to health care during obstetric emergencies (Piet-Pelon, Rob, & Khan, 1999; WHO, 2007c). However, in this study, family planning would be seen to work counter to the cultural desire for a woman to bear a surviving child, preferably a son as quickly as possible. Besides a general reluctance to use contraceptives due to high infant mortality and the desire for sons, it is speculated that the stronger aversion to vasectomy is also related to male identity *(Purushatwa)* which is mainly about proving a man's ability to father children. Men are considered to lose their male identity and become weak after having had a vasectomy.

The third theme in this chapter is: perception of childbirth as a polluted event: birth in *Gotha* (cowshed), and giving birth alone (Figure 7.3). The construction 'birth as a polluted event' can be explained in a holistic manner by referring to the work of Mary Douglas: 'Purity and Danger: an analysis of concept and taboo' (Douglas, 2013). Douglas explains that 'pollution', though linked to hygiene and infection in everyday English language, is understood differently in different cultures. She describes pollution as 'dirt' or 'uncleanness' as a 'matter out of place', and adds that what is considered 'pure', 'edible', 'touchable' or 'clean' is religio-culturally situated, and is done so with an implicit desire to maintain an order in their system. As of the present study, the blood lost during menstruation and childbirth is considered dirt which the families want to keep away from the main part of their homes. The fear of *Dewata* becoming unhappy if a "polluted" or "dirty" woman stays inside the main part of the home where Gods are worshipped (Chapter Six) and when no separate room or an adequate separate space can be spared in the house, the *Gotha* becomes the only place to live during birth and the immediate post-natal period. Both mother and baby are considered polluted and untouchable until a specific date when a ritual purification day is observed, which is usually decided by a local priest or a faith healer. Abiding by such practices is strongly regarded as a woman's religious duty (Figure 7.3).

Segregation or confinement during the postnatal period and considering childbirth as a form of pollution is noted in previous studies from India (Bandyopadhyay, 2009), Bangladesh (Darmstadt, Syed, Patel, & Kabir, 2006; Tarafder & Sultan, 2014; Winch et al., 2005), and in Nepal (Kaphle et al., 2013; Sharma, van Teijlingen, Hundley, Angell, & Simkhada, 2016). Bandyopadhyay described that the confinement of mother and baby after birth is a cultural tradition in India, followed due to a belief that the placental/postnatal blood is impure. The birthing woman herself is believed to be in

danger (in an inauspicious period) and can infect/pollute others. Another reason for confinement is believed to isolate the baby from visitors to protect from infection. Confinement during menstruation and the birth/postnatal period is considered as a form of temporary pollution, whereas the belief that lower caste people are not pure, particularly for holy rituals and should not touch a person belonging to an upper caste is described as a permanent form of pollution. Studies from Bangladesh describe the locals keeping both mother and baby strictly confined, generally up to nine days (which can sometimes go up to 40 days) in the place of birth is to protect the mother and baby from malicious spirits. A previous study in Nepal has describe birth pollution as ritual tradition followed by the locals that makes them feel culturally safe during and after birth (Kaphle et al., 2013), and a period during which the locals consider that it is essential to confine women to heal themselves, as they are perceived to have become weak after birth. These studies have ignored to look into the fact that such practices at the same time deny a woman and her baby access to even basic health care. The present study highlights that the fact that due to the ritual pollution, the occurrence of childbirth in the Gotha (cowshed) in the study villages is nowhere near the common international debate about 'home versus health facility births' or 'unskilled (lay attendants) versus skilled attendants'. The present study reveals that the practice of ritual pollution not only confines a woman and her baby in the *Gotha,* but also compels women to give birth unaided and isolated without letting others touch the delivering mother (Figure 7.3), both to protect others from pollution but also as a sign of being a strong woman birthing alone. As discussed earlier in Chapter Six, perinatal deaths during this period of isolation are matters of little concern, and often rationalised to be the results of *Lekhanta* (destiny). Such a context in these villages is therefore likely to be a cultural barrier to seeking health care and helps maintain the high vulnerability of newborn babies to poor perinatal survival.

Figure 7.3 Perception of childbirth as a polluted event

Source: Drawn by the author based on data analysis
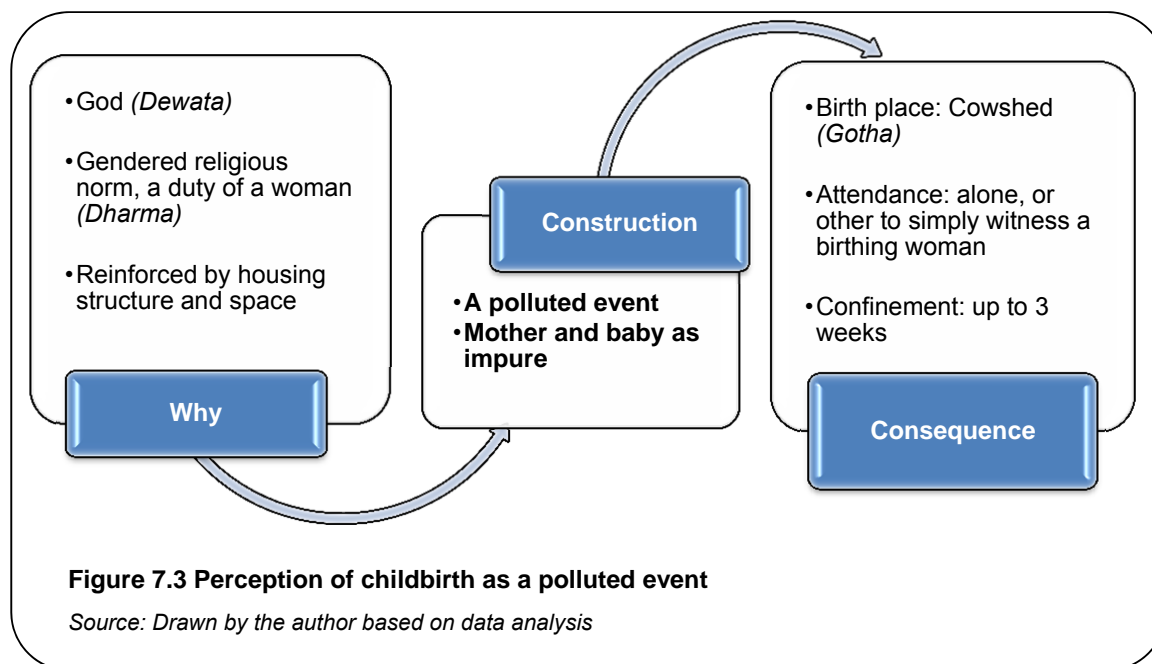
Medical evidence shows that the time around birth is the most critical time to save the lives of a large number of mothers and babies (Dickson et al., 2015; Lawn et al., 2014). Nepal's health policies discussed in Chapter Five and other studies (Lawn et al., 2005; Shrestha et al., 2012; Wagle et al., 2004) encourage women to deliver their babies at health facilities to avoid potential risks of infection and death of mother and baby, especially during obstetric emergencies. A skilled attendant at birth is considered essential even if it is a homebirth. Far from delivering in a health facility (birthing centre) with skilled birth attendants, which the national health policies aim for (Chapter Five, Section 5.3), the present study found that women end up giving birth, not even in a clean place at their home, but they give birth alone and unaided in *Gotha,* which for most purposes is hardly clean, safe and comfortable. The lay attendants, namely close family members of the delivering woman, even the mother, sister and mother-in-law, if present, are mostly witnesses to the birth from a distance. They hesitate about touching a delivering mother as well as babies, unless the mother is not able to deliver on her own and cut the baby's cord by herself.

The study explored that the practice of abiding by the idea of ritual pollution is often related to their *Dewata* (God). It is considered as a woman's religious duty *(Dharma)* to strictly follow the norms to abide by the idea of ritual pollution. Seeking health care from health facilities and skilled birth attendants is mostly compromised during this polluting period. Although locals seek health care and remedies from faith healers, it is found that the faith healers only pray and sprinkle water and rice grains from a distance, and leave the birth place immediately after the birth of the baby. One of the bitter realities which this study has noted, as other studies have not, is that nowhere is it pointed out that the pollution ritual is observed more stringently and for a longer period (16 days to three weeks) in the case of the birth of a female child. The birthing mother and her baby are considered less polluting when a baby boy is born, and the polluting period is usually shorter

resulting in a shorter confinement. In many families, the mother and baby enter the main part of the house for *Chhaith*, a ritual celebration which is usually on the 6th day after birth of baby boy. Therefore, it puts baby girls after birth in a more vulnerable position due to a longer period of isolation.

The findings of this chapter have strong policy and programmatic importance. This study has affirmed that the gender related cultural context has been a key vulnerable factor to produce ill health in the mother and baby, and it remains as a barrier to seeking health care. Immediate attention is needed to address factors, such as the rituals associated with birth pollution, confinement in the *Gotha*, leaving the woman to deliver and cut the umbilical cord herself, lack of emergency obstetric care and even if there is such care, it is provided by a faith healer. In addition, it is proven that increasing access to contraceptives through health facility settings (Blank, Baxter, Payne, Guillaume, & Squires, 2012) and abstinence education and contraceptive promotion in educational settings such as schools and colleges through school based education and peer education (Blank, Baxter, Payne, Guillaume, & Pilgrim, 2010) are a key to prevent conception/unintended pregnancies and delay spacing in young people. This study strongly recommends men's education (often young boys who get married to even younger brides) to practise family planning and postpone the first birth until the girl is 20 years of age. It is understood that changing the deeply rooted cultural beliefs is not easy, and cannot be quicker. However, unless policy makers and managers in the health sector duly acknowledge the implications of the local beliefs and practices, the medically oriented training packages alone will have no impact, or a very low impact, in the study regions.

This study recommends that maternal and child health programmes should be strongly integrated with family planning programmes, and that the local health system should pay more attention to promote family planning services. However, the context of high perinatal mortality is related to participants' belief that *Dewata* (God) becomes unhappy with the use of contraception (see Chapter Six), and that of the fear of losing a child and becoming child less (mostly a baby boy). Avoiding contraception until a child is 3 to 4 years old is considered a wise decision in their context. Having repeated births is regarded as the only immediate option to have a surviving child. Poorly functioning health care (discussed later in Chapter Eight) that neither provides contraceptive choices to the villagers, nor educates/promotes the use of family planning is another factor which has to be seriously taken to promote family planning practices in the study villages. Another key factor observed in this study is that some women, despite their decision to use hormonal contraceptive (injection of progesterone), did not trust the quality of the contraceptive provided at government health facilities—with the suspicion that they might be given expired drugs/contraceptives which remained for indefinite time in the local health facility store, often without anyone checking them. In the absence of adequate counselling, women stopped using hormonal contraceptives after complaints of spotting, which however is a normal side effect of the

injectable hormonal contraceptive. In a hope to receive a quality drug/contraceptive, it was found that a few women dared to buy them from private drug stores. It was seen during the fieldwork that public health facilities, despite calling themselves 'client/adolescent friendly', the 'condom box', was hung neither from an appropriate height and private site of health facility, nor it had any condoms inside it. The government's slogans about providing family planning counselling and contraceptive choices are simply statements reiterated in papers/reports.

Maternal and newborn health policies and programmes should strongly aim to prevent child marriages and son preference, which is, however, barely stated in Nepalese policy documents [see Chapter Five]. Reducing poverty, empowering women, and access to quality education for girls are frequently referred as the most effective interventions to prevent child marriages and son preference (Human Rights Watch, 2016; Ware, 1981). Apart from a long-term focus on women's empowerment and education for girls, participatory interventions mobilising women's group (Manandhar et al., 2004; O'Rourke et al., 1998), and local stakeholders' group (Persson et al., 2013), which are proven interventions to tackle high neonatal mortality could be utilised to educate communities to prevent discriminatory norms and values about child marriage and son preference. Inter-sectoral efforts at different settings (schools, health facilities, parent groups, and faith/religious groups) may be useful to break the notion of the girl settlement *(Gharbar)* that perpetuates the loop of child marriages, early and repeated pregnancies, and persistent perinatal deaths in the villages. It is this construct of girl settlement, backed up by the discriminatory norms and values that makes it so powerful that child marriages and son preferences continue in the villages despite legal measures (DoHS, 2016; Human Rights Watch, 2016). It has contributed to the persistence of vulnerabilities of newborn children to perinatal deaths, has let this vulnerability remain unchecked, such as in the villages by not registering any marriages, births and deaths before they reach legal minimum age. Making every death count and visible is one of the strategic actions strongly emphasised in policies (UNICEF and WHO, 2015; WHO, 2014c). The implementation of birth registration, birth and death certificates in such a context as in the study villages from Nepal, is practically non-existent. It is therefore strongly recommended that health policy makers and programme managers understand this construction of girl settlement (Section 7.1.1) and its relation with child marriages, son preferences, and tailor the interventions accordingly. In addition, as I found out, there exists rampant sex selective abortion in the villages, and preferential attitudes to son (baby boy) among health volunteers and health workers. Under these circumstances, it is almost certain that the government's rural ultrasound programme (FHD, 2013) provides parents with the means of detecting the sex of the foetus and terminate the pregnancy if it is a female foetus in order to satisfy their desire to have a son. This further engenders such male oriented gendered values, which the policy and programme implementers need to be aware of. In addition, as seen in this study, continuous abortions and perinatal deaths followed by poorly spaced pregnancies of young women still in their teens contributes to an

increased risk of keeping perinatal mortality high in the villages. In-depth investigation of sex-selective abortions is not within the scope of this study, but I suggest that future medical investigations should find ways and means of checking these rampant sex-selective abortions, by taking action on two fronts—cracking down on abortions on demand by qualified and non-qualified persons and by continuously educating parents and the general public about the value of girls and at the same time creating government and societal support to empower women.

As discussed above, the triad of gendered intra-familial dynamics (relationships among a mother-in-law, husband and daughter-in-law) has shaped women's and families' construction that pregnancy and birth are not special events in their lives. Women and families in the villages consider that if these are natural experiences, they are not special experiences. The reason behind such a consideration is the intra-familial context which has normalised pregnancy and childbirth events as everyday (ordinary) events. The low voice of pregnant mothers (daughters-in-law), controlling (often negative) mothers-in-law and disengaged men (husbands) in pregnancy and childbirth related care and support have made the events of pregnancy and childbirth less valuable than a priority for daily duties (household and agricultural). Therefore, recommending quick-fix medical solutions alone is not enough unless policy makers and programme implementers acknowledge and understand the power of this intra-familial context which has shaped women's pregnancy and childbirth experiences in the villages. Only then, the enlightened purpose of contemporary discourse about the natural versus medical dichotomy in pregnancy and childbirth (Brubaker & Dillaway, 2009; Mansfield, 2008) could be made practically possible to these young mothers (daughters-in-law) in the villages. In the natural dichotomy, a woman is considered as the key agency of her pregnancy and childbirth (Brubaker & Dillaway, 2009). She is put at the centre of her choices regarding birth setting and use of medical technology. However, the young mothers in this study do not have any choice. At the family level, it is about the value of pregnancy and childbirths rather than a choice about natural or a medical model. Programmes need to focus on creating an enabling environment for these young mothers within a family and create value for pregnancy and childbirth events. Maternal and newborn health policies which merely state 'women-friendly' or 'rights based programming' (Chapter Five) are not enough unless such policy values are implemented.

Understanding the intra-familial context is vital to leverage the effectiveness of family and community-based interventions. This is important because decisions regarding pregnancy and childbirth matters are up to family members. The position of a woman (girl) is already weak due to the gendered motive of girl settlement, which further intersects with her weak position within her in-law's family and puts her in a fragile state. Due to the hierarchical family structure and power imbalance, only targeting young mothers is not effective. Engagement with family members particularly mothers-in-law and husbands is an important part of the community engagement strategies. Disengaging mothers-in-law in particular could be perceived as a challenge as they fear

the loss of their power, and may become further controlling and hostile towards their daughters-in-law. Likewise, keeping men disengaged from their wives' pregnancy and childbirth would perpetuate a gender stereotype that pregnancy and childbirth are women's only matters. Otherwise, the list of family and community-based maternal and newborn health interventions as suggested in a range of studies (Bhutta et al., 2005; Bhutta et al., 2014; Darmstadt et al., 2005) are less likely to be successful. Mobilising and empowering women and families to demand skilled care is the essence of family and community-based maternal and newborn health interventions. Mobilisation of parents and families and raising their voices has been targeted as one of the key strategic activities in the Every Newborn Action Plan (WHO, 2014c), and by the Lancet's 'Ending Preventable Stillbirths' series (de Bernis et al., 2016). In this regard, this study strongly recommends policies and programmes to consider gendered intra-familial contexts, only then the essence of family and community-based interventions could be implemented, and could help make an accelerated reduction in perinatal deaths in the rural areas.

Ensuring men's involvement with their wives during labour, both at homebirth and health facility births could be part of an intervention in the future. Likewise, rather than focussing on current women's only groups, namely the 'Mothers Group' (Manandhar et al., 2004), mixed sex groups could be beneficial to reduce gender stereotypes and to sensitise men in supporting pregnancy and childbirth. Such mixed-group approaches have not been tried before in the study area, or in Nepal as a whole. Therefore as a first step, it is recommended to investigate current policies and programmes such as mobilisation of only female community health volunteers in Nepal (MOHP, 2010), and group based education to only pregnant women's groups to see whether such approaches have, in the long run reinforced gendered stereotypes of pregnancy, childbirth and newborn care as women's only responsibilities.

In the literature, perinatal survival is predominantly seen through a bio-medical lens, focusing on prematurity, asphyxia and infections as the main causes of stillbirths and neonatal deaths (Lawn et al., 2014; Lawn et al., 2016; Lawn et al., 2005). Studies describing gendered aspects of stillbirths and neonatal deaths either do not see gender as relevant considering that preventing stillbirths and neonatal deaths requires a technical/bio-medical focus. This is partly because studies often conclude with the evidence that newborn girls are biologically stronger and have greater survival chance (Fuse & Crenshaw, 2006; Ulizzi & Zonta, 2002). Gender, if discussed, is limited to describe the distribution of sickness or deaths across baby boys versus baby girls (Rosenstock et al., 2013; Rosenstock et al., 2015). The focus is emerging, yet this is mainly in describing the outcomes (sickness, deaths), rather than exploring gendered aspects which has led to these outcomes. The policy documents (see Chapter Five Section 5.3) refer to 'gender equality' in newborn care; however, it is merely a statement with little evidence of why and how gender should be considered in the implementation of maternal and newborn health interventions. In the policies, stillbirths are not even considered from a gender perspective. In 2011, UNICEF produced a narrative synthesis

of 117 studies which discussed gender influences on child survival, health and nutrition (UNICEF, 2011). Throughout the synthesis, stillbirth does not even appear as a term, and neonatal mortality appears scantly when describing the impact of women's group led community mobilisation intervention and effect of domestic violence in reproductive and neonatal health. The present study strongly recommends that poor perinatal survival (stillbirths and neonatal deaths) should rather be seen as an outcome of gendered construction. The three themes discussed in this chapter are interrelated with gendered constructions existing in the patriarchal, patrilocal and socio-cultural contexts of the Nepalese mountainous villages. The gendered norms, values, roles (labour) and access are discussed as key inter-related aspects in gender study and programming (LSTM, 1999). It is evident from the above discussion that the three emerging themes of the present study have described the complex inter-relations of the norms, values and roles. The commission on social determinants of health recognises gender as a key social determinant of health, and describes that health care within and outside families is affected through different routes such as gender relations of power in norms, values and access. Emphasising the importance of gender, the commission report mentions: "The intergenerational effects of gender inequity make the imperative to act even stronger. Acting now, to improve gender equity and empower women is critical for reducing the health gap in a generation" (CSDH, 2008, p. 145). It is therefore imperative to acknowledge and understand gendered cultural context as an agenda of community health in advancing the poor perinatal survival in the villages.

7.5 Conclusion

This study argues that poor perinatal survival, in developing countries such as Nepal, should be seen as an outcome of gendered constructions along the pre-pregnancy, postnatal continuum comprising a girl *(Gharbar),* a pregnant mother (daughter-in-law), and a woman and baby at and after birth (ritual pollution). These constructions have compromised care and support during pregnancy and childbirth, and have rendered them as non-special events in the lives of women in the study villages. Perinatal survival should be seen as a 'social construction of gender', thus not just limiting it to an indicator of quality of care (de Bernis et al., 2016; Dickson et al., 2015; WHO, 2014b) which predominantly is a medical construction. Only then, would we be able to see the complex gendered contexts in service planning and programme implementation. This will also facilitate the formulation and implementation of appropriate policies, thus moving away from merely acknowledging 'gender equality' on paper. Discussing gender with simple disaggregation of sickness and deaths under the dichotomies of baby boys and baby girls will have less impact in advancing the poor perinatal survival unless programmes are tailored to address the gendered norms, values, beliefs and expectations arising across the pre-pregnancy to postnatal continuum.

Chapter Eight discusses health care delivery contexts of poor perinatal survival in the study villages.

CHAPTER EIGHT

HEALTH CARE DELIVERY AND PERINATAL SURVIVAL: APPROACH, QUALITY AND HEALTH GOVERNANCE CONTEXT

The previous chapter discussed the gender constructions and culture which have perpetuated poor perinatal survival in the mountainous villages. The perceptions related to girl settlement *(Gharbar)* and son preference have been strong factors driving child marriage, early and repeated childbearing. The gendered dynamics of relationships and power within the family structure have shaped the perception of pregnancy and birth as mundane, and not special events, and birth preparedness as a practically non-existent concept. Childbirth is considered as ritual pollution, which has led villagers to choose *Gotha* as the birth place, and to let the women give birth alone (not even assisted by a member of the family). This is occurring at a time when national health policies have an emphasis on skilled birth attendance and health facility births as the most critical strategies tackling the high prevalence of neonatal deaths. The present chapter examines the health care context in the study villages that influences perinatal death. The chapter is presented under three themes as outlined in Figure 8.1.

3.1 Approach of health care delivery
Low focus on empowerment and engagement

3.2: Quality of care
Poor acceptance, unsafe and uncomfortable in health facilities

3.3: Local health governance failures
Health governance failures in delivering pregnancy and childbirth services

Compromised access to basic health care for mother and newborn

Figure 8.1 Declining essence of primary health care and health system failures

Source: Drawn by the author based on data analysis

8.1 Approach of Health Care Delivery: Low Focus on Empowerment and Engagement

The approach to health care delivery in these villages lags far behind the comprehensive primary health care approach enunciated at Alma Ata (WHO, 1978) that considers an integrated (including preventive, health promoting and curative aspects), and inter-sectoral and people-centred approach. People-centred care is one of the key attributes of quality of care, and community engagement which in this study means engagement of women and families is a crucial aspect to improve quality of maternal and newborn care (WHO, 2017d). Interviews with a range of participants in this study, as well as field observations, have shown that health services are limited to the provision of a number of medicines, and institutionally focussed visits during pregnancy, birth and postnatal period. As found from the study, community and home based maternal and newborn interventions (Bhutta et al., 2005; Darmstadt et al., 2005), engagement of women and families to sensitise and empower them to demand care, as also targeted in Nepal's national policy documents (Chapter Five, Section 5.3) are not realised in practice. The health volunteers and the local Mothers' Groups (MG), which are the foundations of the Nepalese community health system, have not been mobilised to their full potential. Each female community health volunteer is supposed to mobilise a group of women called a Mothers' Group, in her workplace (village settlement), to empower women and educate them in maternal, newborn and child health (New ERA, 2007). Health service providers are supposed to meet regularly, facilitate the health volunteers and ensure that the Mothers' Groups are functioning well. However, the female community health volunteers rarely meet; they are occasionally called to health facilities during national immunisation or Vitamin A distribution campaigns. Consequently, the monthly progress records about the Mothers' Groups which the health volunteers prepare are often just false records.

Becoming a 'Doctor' and supplying medical tablets

Health care, from the viewpoint of the primary health care providers, is perceived only as medical care. Almost all health providers interviewed are assistant health workers (nurses, auxiliary nurse midwives, auxiliary health workers, health assistants) and community health workers such as female community health volunteers who comprise the majority of health workforce at primary health care level in Nepal. Such a perception has impacted on the role of the health service providers, who practise their professions from within the confines of health facilities and dispense basic medicines. There is a lack of willingness amongst the health providers to actively engage with community members. Mobilisation and empowerment of women and families to advance care and survival of mother and babies are not viewed as health care providers' responsibilities. Such understanding is further influenced by their perceived social image as a medical 'doctor' although none of them is qualified as a medical doctor. A doctor is valued as someone who speaks little with clients, stays in a health facility, checks a patient with a stethoscope (*Ala)*, and prescribes tablets.

This is far from the principle of comprehensive primary health care which emphasises community involvement, integration, empowerment and health promotion as key principles (WHO, 1978). The comprehensive primary health care approach aims to enable people to gain control over their own health, to be sensitised of their right to health care, and to enable them to decide on and demand health care. However, in the study villages, the service providers have paid very little attention to community engagement, health promotion and disease prevention. One of the community health workers summarised the situation as follows:

> *Everyone [other health workers] including a female community health volunteer is a doctor here. This is the image that has built-up for a long time in our society. They are not interested in preventive and promotional activities. They feel themselves to be like a medical doctor when they can prescribe tablets, and put Ala (stethoscope) on a patient's chest. (Community Health Worker, HSP15)*

While staying in health facilities, I noted that health education was limited to the distribution of educational brochures and leaflets to a handful of women who could make health facility visits and who are barely literate. There was no two way interaction between the women coming to health facilities and the health care providers.

The perceived self-image of being a medical doctor has shaped the behaviour of the primary health care workers. The health service providers, including health volunteers feel valued when they are treated as doctors by the women and families in the communities, who respect and acknowledge any health worker and call her/him a doctor. This reinforces the service providers' intentions to exercise professional power, to bolster their self-image, and reframe their roles. Women in the villages call any male health worker, including a member of support staff (such as a peon[15]) a doctor (*Doctar or Doctorsab)*, and a female health worker including the female

community health volunteers, a female doctor *Doctarni or Doctornisab)*. The local terms, particularly *doctorsab* or *doctornisab* are terms denoting a higher social status than that of the women and families in the communities.

Plate 8.1 Supplying those few tablets is everything about Primary Health Care (in health facility in the second village)

[15] A peon is a support staff member in a health facility. S/he acts as a security guard of the health facility who ensures that the health facility premises are clean, ensures functioning of toilets and availability of water. During meetings and training in the health facilities, s/he ensures management of tea and snacks as ordered by staff in the health facility. S/he also works as a helper/porter to bring medicines and vaccines from the district level to the villages, and is supposed to provide any other non-medical help as told by health workers.

A health facility is seen by the women and families as a place to receive tablets *(Tata)* (Plate 8.1). They do not care much about whether they receive skilled care during their visits to the health facilities as long as they receive basic medicines in the form of tablets, such as vitamin B, iron, anti-worm, antacids, pain medications etc. This is seen to reinforce the view that the health facilities function simply as a store which dispenses basic tablets by a non-skilled support staff member who is also regarded as a doctor. The support staff are meant to clean and maintain the health facility, to ensure availability of water and to guard the health facility. One of the support staff stated:

> *Villagers come early in the morning asking for tablets (Tata). We don't need to open the health facility during the daytime; no one comes during the daytime. They themselves say, 'why do you suffer coming here during the day time? You can give us tablets early in the morning and then you can go back, that is okay'. (Support Staff, HSP6)*

During a post interview chat, it became clear that the support staff feel proud of their ability to prescribe iron tablets, anti-worm tablets, and even Tetanus Toxoid (TT) injections to pregnant women. This is related to their perceived self-image of being a medical doctor.

Although the perception of health care as solely the provision of basic medicines has been transferred to community members, there are some women and families who feel dissatisfied when they are not provided with enough information about the causes of the mother's and baby's sickness. Binita's husband described his sorrowful experience of seeking care from a local hospital after his wife's first pregnancy ended in a stillbirth and the sadness of receiving treatment for his sick baby during his wife's second pregnancy. Binita, (Chapter 7, Box 7.2) aged 20, lost her first baby in her womb, and the second baby in a hospital as it suffered from a cough and cold from the second week after birth.

> *Sometimes, they [health workers in the village health facility] say they don't have tablets (Tata: basic medicines). If they don't have tablets, why can't they educate us? Why don't they tell us about what has happened to our babies? We just have to return without any care; they don't talk to us about the sickness. It is so sad. If we go to the hospital, they merely touch you with their hand and put that equipment [stethoscope], they don't explain the problem, and hardly give us even one tablet. We have to go to drug sellers [to buy more tablets] anyway. So, now I feel that if I have money, it is better to go directly to these local drug sellers (pharmacies). (Binita's husband, a 26 year old father)*

The focus on supply of tablets as the only responsibility of health workers has restricted their role in providing a more comprehensive health service to the community. They do not engage with women and their families to give them health education and counselling about their health. As described above, at primary health care level, health promotion and prevention are considered major activities both internationally (WHO, 1978), and also stated in national policy documents (Chapter Five, Section 5.3). Health care is expected to be brought closer to communities and homes. Although community visits and engagement are an essential part of their duties, the health service providers do not consider it worthwhile visiting the communities for routine outreach services. One of the female community health volunteers stated:

I don't know why they lose babies. They have a check-up in pregnancy; also they take anti-worm tablets and have a tetanus injection. We don't have anything more here [other medicines]. We only get a few tablets. The village women don't understand. They think we keep tablets for our personal use only. Everyone says we just hide these tablets for ourselves. We have Cotrim [antibiotic] for pneumonia, Albendazole for worms, Zink, Oral Rehydration Solution and iron--that is all we have. (Female Community Health Volunteer, HSP11)

Such a narrow view misses a range of other socio-cultural and health care aspects of quality care and support needed during pregnancy and birth that is of critical importance during healthy pregnancy and childbirth. Female community health volunteers are considered as pillars of Nepal's community health system. The critical role of the health volunteers as community mobilisers to empower women to demand skilled care, as intended in the policy documents (DoHS, 2015), is limited to distributing only medicines and tablets. Promotion of healthy pregnancy and postnatal practices, and taking the social determinants of maternal and child health are all unrecognised due to an over attention to the provision of basic medicines as the only means of health care. Little emphasis is placed on preventive and health promotion interventions such as those about the role of families in care and support during and after pregnancy.

The cash incentive strategies introduced by Ministry of Health for women (MOHP, 2006b, 2007, 2013), and female community health volunteers are primarily to encourage women to attend a health facility to give birth. A pregnant woman is paid about 19 AUD as an incentive to motivate her to attend a health facility to give birth. The local health facilities in the study villages has set less than 1 AUD (50 Rupees) for a female community health volunteer for every woman sent to give birth in the health facilities. This strategy has resulted in some negative consequences by moving further away from community-based interventions to a sole focus on the number of women referred to health facilities.

Here in this village, the village council has arranged 50 Rupees [AUD: 60 cents] as an allowance for a female community health volunteer if she brings a woman to deliver in a health facility. The more women she sends to the health facility; the more money she receives. Health volunteers have left their job as a health educator, and health workers pay no attention to attend homebirths. (Senior Auxiliary Nurse Midwife, HCM3)

Home and community visits as mere slogans

The delivery of primary health care in the mountainous villages of Nepal is confined to the health facility premises. Health workers rarely visit homes and communities to provide, or talk about primary health care, although this is described as one of their main roles in the villages (MOHP, 2004b). Health service providers simply wait for women to come to the health facilities for their antenatal check-up (ANC) and childbirth rather than creating awareness in the women about the importance of ANC visits or assisting women during homebirths and postnatal visits. One of the auxiliary nurses explained the situation as follows:

We call women to the health facility here. We don't go to attend homebirths. Only women from nearby [only one settlement, there are five settlements in this village] come to contact

Despite policies discouraging homebirths, almost two-thirds of the mothers still give birth at home (DoHS, 2014). An example of the strategy to discourage homebirths is the discontinuation of the supply of safe delivery kits (SDKs) to the villages seven years ago. A safe delivery kit was provided to ensure safe and hygienic homebirth and to prevent infection which is a common cause of morbidity and mortality of women, and the most common cause of neonatal deaths. The kits contain a plastic liner to put on the surface during birth, sterile blade and string to cut and tie baby's cord, and soap to wash hands. Women are still seeking SDKs, although it is more than seven years since these kits were supplied to these communities. One female community health volunteer shared her views as follows:

We got the Kits [Safe Delivery Kits] just once from a non-governmental organisation. It is about seven years since they stopped supplying them. We asked health facilities to supply them, but we didn't get them. Women shout at us, 'you gave us kits before, but not now, why?' They don't supply these Kits now. We don't have them [Kits) from anywhere. What can we do?' (Female Community Health Volunteer, HSP11)

In the villages under study, community health workers (female community health volunteers, Mothers' Groups and outreach services with maternal and child health workers and village health workers) have become dysfunctional, and community and home visits are mere words acknowledged on paper.

A member of the support staff from the health facility explained:

I have never seen any health worker coming to our community to conduct the Outreach Clinic. The health institution has declared my house as a centre for the Outreach Clinic. The medicine box [first aid and basic drugs for outreach services] has been stored there for more than one and a half years. They (health workers) say they conduct outreach, but I have never seen them here [in the Outreach Clinics site]. They just lie about it, merely reporting on paper. It is a cheating. (Support Staff, HSP6)

Another local auxiliary nurse reported that she had only run an outreach clinic (ORC) once in the past two years of her stay in the health facility. As per the local health facility target, such clinics should be run at least once every month, i.e. three such clinics in the first village, and five in the second village during the fieldwork period.

As is implicit in the support staff (HSP6)'s excerpts above, the value of the outreach service has been reduced to a 'box of tablets' containing some pain medication, antacids, packets of oral rehydration solution (ORS) and medications for diarrhoea control and skin infections. Routine outreach services are supposed to counsel and educate women and families about family planning, pregnancy and postnatal care; conduct immunisation; and treat common diseases such as pneumonia, diarrhoea and wounds etc. Although the Outreach Clinics are not functioning, these are simply ticked as functioning in the monthly service reports.

Women in the villages are at a double disadvantage: they have received neither any care from the community outreach, nor any quality care from health facilities. Care during pregnancy is limited to recording the number of visits (contacts) in the antenatal registers. The possibility of delivering care in the study villages, where most women prefer homebirths has been limited by the mere focus on health facilities with little attention to home-based pregnancy and childbirth services. However, assisting women with homebirths, it is worth noting that the local health system pay attention to prevent births in *Gotha* (cowshed). Each pregnant woman should be seen for an antenatal check (ANC) once a trimester. But the health care providers schedule ANC visits on a fixed day every month so that they can be free on other days. Since a trimester comes on different dates for different mothers, fixing a particular date of every month limits the chance of a pregnant woman seeking ANC at her own scheduled time. The absence of health personnel in village health institutions is an issue further constraining access to health care services in villages:

> *I went there [village health institution] once a month to conduct antenatal check-ups and immunisation. We have antenatal day on the 17th of every month. There is no work. You remain idle in the health institution. They want medicine tablets at home. I did not feel like staying there. Women do not want to come to the institution. Therefore, the birthing centre also could not continue to function in the health institution. (Auxiliary Nurse Midwife, HSP3)*

8.2 Quality of Care: Poor Acceptance, Feeling Unsafe and Uncomfortable in Health Facilities

Quality of care has multiple aspects such as safety, effectiveness, timeliness, efficiency, equitability and the ability to be people-centred (Donabedian, 1988; WHO, 2017d). The World Health Organization's health system approach suggests that quality in maternal and newborn care could be examined from two dimensions: provision of care and experience of receiving care (WHO, 2017d). Aspects related to workforce and availability of physical resources are categorised as cross-cutting—applicable to both the care provision as well as experience of care by users. In this section, quality of health care is examined in terms of women's and their families' experiences related to safety, comfort and respect in the health facilities, and their acceptance of recommended newborn care. Lack of freedom and autonomy during childbirth, and the service providers' inappropriate behaviour, are key factors behind feelings of being unsafe and uncomfortable in health facilities. Women feel unsafe in the health facilities due to their lack of confidence in the provider's competence, and doubts and fears concerning perinatal deaths during and after a health facility birth.

The following section describes the most common care practices as reported in the villages.

8.2.1 Care of a Newborn Baby: Poor Acceptance of the Recommended Care

Newborn care practices recommended by health facilities (DoHS, 2015; MOHP, 2004b) such as postponing bathing at least for the first 24 hours after birth, wearing warm and soft clothes immediately after birth, immediate and exclusive breastfeeding, and keeping the baby in skin to

skin contact with the mother are poorly accepted by the women. In some cases such recommendations are in conflict with local cultural beliefs and practices.

Baby is not clean and active unless bathed

Postponing bathing for at least first 24 hours and keeping the newborn baby warm with soft and clean clothes are the national policy recommendations to prevent hypothermia (MOHP, 2004b). However, bathing a baby immediately after birth is a common practice in the study villages. The comfortable and cosy environment in the mother's womb is considered to have made a baby lethargic *(Astadiyeka)*. Therefore, an immediate bath with cold water is perceived to make a baby active and initiate his/her cry. Bathing is also considered essential to clean the baby's skin and make a baby look good. Punchamaya (Chapter Six, Box 6.19), pregnant with her 10th child said:

> *When we bathe them with cold water, they will be active and you can hear baby's cry ('Umm Gaa'). This makes the baby healthy and appear good. So, immediately after birth (Hudaina Sahita), it is good to bathe them with cold water. You can use warm water later. Baby is covered with the dirty thick white substance (Leiu: vernix), sometimes also blood in it; it looks filthy (Sisiko). This can infect the skin (Chhala Pakne). When we bathe the baby with soap and water, it cleans the skin well. Now, baby looks clean and good. (Punchamaya, a 35 year old mother)*

Drying a newborn with a cloth is considered invasive to their delicate skin and therefore a soap and water bath is considered appropriate. Punchamaya added:

> *The nurses in hospital tell us, 'don't bathe' – how can it be clean without bathing? The nurses tell us to dry with [the baby] with a piece of a cloth. A newborn is just out from the mother's womb. Newborns' skin is soft like an egg's outer membrane (Jala). It is very delicate. If we dry the baby with cloth, the skin can tear. (Punchamaya, a 35 year old mother)*

Some women do not like the appearance of their baby's skin and its smell until their babies are bathed. Karmajong said:

> *If we don't bathe them, the baby looks filthy; it is not a good look (Siksiko). I don't like the smell. We bathed our baby. (Karmajong, a 22 year old mother)*

> **Karmajong** is a 22 year old woman, illiterate and from the *Lama* community. She married at 18, has a baby boy, and lost one newborn baby last year on the day of birth. Her husband aged 25 is a farmer. **[Box 8.1]**

It is also seen that some families use lukewarm water if they perceive a baby is active and making a good cry. However, they rarely delay the bath for the first 24 hours. On some occasions, young parents are willing to delay bathing the baby, but it is not possible to do so because of the determination of older family members, usually the mothers-in-law. The majority of mothers (daughters-in-law) are not in a position to bargain in their family.

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Latima (Chapter Six, Box 6.7) is 32 year old woman who has lost seven babies including stillbirths, newborns and infants. Latima's husband intended to delay bathing, but he could not stop his mother from giving an immediate bath to the newborn.

> *...my mother said, 'no, the baby should be bathed, the baby is weak and lethargic (Astadiyako). Then we bathed. [Fortunately, this baby (an eight months old baby boy) has survived]. (Latima's husband, a 39 year old father)*

It is found that villagers also bathe apparently stillborn babies to check to see if the babies would cry, and were still alive *(Paran).* There was anecdotal evidence of stillborn babies evidently coming to life after being given a bath. Although her baby was stillborn, Yanghmu (Chapter Six, Box 6.14) bathed the baby.

> *We also bathed my first baby [stillborn] immediately after birth. This can wake up babies and help them breathe if they are still alive anyway. We bathed the baby three times. (Yanghmu, a 28 year old mother)*

A local health worker also reaffirmed that delaying bathing after birth is not acceptable to the families. He noticed some families merely pretending that they will not bathe their babies, but doing so once the health workers left the scene.

> *No matter how much we ourselves or female community health volunteers tell them not to bathe, they bathe their baby immediately after birth. Moreover, they use cold water to bathe their babies! If they see us nearby, they are afraid and they stop. Otherwise, behind the door, they do it anyway. (Auxiliary Health Worker, HSP7)*

The immediate newborn bath is common also amongst the female community health volunteers. During the recruitment of participants, I visited two female community health volunteers with babies younger than six months old who both reported that they had bathed their babies immediately after birth.

Women are also seen to be hesitant about drying the baby instead of bathing. This is revealed as one of the reasons for the women's low preference to attend birth in health facilities. They feel uncomfortable until both the mother and baby have bathed. Women also commented about the lack of basic amenities such as showers and washing facilities in the health centres. In this regard, homebirth is considered more appropriate. This is also one of the reasons behind leaving the health facility immediately after birth without waiting for a few hours' observation of mother and her newborn after birth.

Newborn babies are too young to wear clothes

Putting clothes on babies immediately after birth is another policy recommendation made to prevent newborns from getting hypothermia (MOHP, 2004b). The newborn care guidelines in Nepal recommend baby clothes such as trousers, woollen caps and socks (*Bhototopi ra Moja)* (FHD, 2013). But, women and their families do not consider it worthwhile to prepare clothes for newborns until they feel confident about the babies' survival. Most families just use a piece of old

cloth to wrap their babies in after bathing. Locally, a piece of cloth is called *Talo*, usually torn from the mother's old sari *(Dhoti)* or shawl *(Barko)* or from her cloth belt *(Patuka).* Junamati (Chapter Seven, Box 7.4), a young mother who lost her two newborns, explained:

> *These (Talo) are pieces of my sari (Dhoti). I used them to wrap my babies in after birth. When a baby is born, we get these saris, tear them and wrap the baby with it. We don't buy any separate clothes [like trousers, caps]. Newborns are very young to put clothes on. (Junamati, a 25 year old mother)*

It is noted that women and their families consider infants too young to wear clothes until they start crawling. They also feel that putting clothes on newborns is difficult. Fuladevi's (Chapter Seven, Box 7.9) husband who lost his baby last year on the second week after birth, said:

> *...it is not necessary to have clothes for infants until s/he starts crawling. It is difficult to put clothes on them. Other old pieces of cloth (Talo) are enough. (Fuladevi's husband, a 19 year old father)*

It is revealed from this research that baby boys in some families are more likely to have clothes earlier as gifts during *Chhaith* (the sixth day ritual after birth)*.* Yet, families do not like to use these clothes until the baby grows older. Wearing new clothes early after birth is believed not to bring good fortune. The old clothes are not usually clean, thus they are likely to cause skin rashes and infection. They are also not enough to protect the baby from the cold.

Some women and their families were surprised when I was discussing whether they had clothes for their newborn after birth. For example, Shivakumari (Chapter Six, Box 6.12) expressed her amusement:

> *....that was a very young newborn [died on the 7th day after birth in Gotha], why does he need clothes? [Surprised]. We don't know whether the newborn survives. We don't buy clothes until a baby starts crawling, better to buy when they start stepping. (Shivakumari, an 18 year old mother)*

Women and their families do not feel the need to buy clothes in preparation for childbirth. Pregnancies and childbirth are considered as natural to the extent that they require no special preparations (Chapter Seven, Section 7.2). It is not known where a woman is going to give birth: on the way to the field or home, in the farmland or in a forest.

During my stay in a local hospital, nurses explained that women coming to hospital never brought any clothes for their unborn babies. Due to this, hospitals have begun to provide clothes, yet the mothers do not use these clothes until the babies are about seven months old.

It is not only the women in the communities who prefer not to prepare baby clothes as recommended, but the female community health volunteers also agree:

> *I just wrapped the baby with a blanket; we brought clothes on the 11th day when I entered the home. (Female Community Health Volunteer, HSP10)*

Breastfeeding: colostrum is indigestible, feeding baby after birth and disposal of the placenta

Evidence suggests that babies are to be breastfed immediately after birth (Edmond et al., 2006; WHO, 2016). This helps to establish a bond between the mother and her baby, the baby learns to suckle mother's milk, and it also prevents neonatal hypothermia. The first breastmilk after birth known as colostrum has an anti-infective property and is rich in protective factors (WHO, 2016). Breastmilk contains all the nutrients required for an infant up to six months, and protects the baby from common problems such as diarrhoea and pneumonia (WHO, 2016). However, in these villages, it is uncommon to breastfeed a newborn baby before the birth of the placenta *(Salnal Saffa)* and bathing after birth. Jasikala (Chapter Seven, Box 7.10), who lost her two newborns in her previous pregnancies, said:

> *If the placenta is delivered quickly (Salnal Saffa), the baby could be breastfed within an hour. Otherwise, it takes time. It might go two hours or even longer if the placenta isn't delivered sooner. (Jasikala, a 19 year old mother)*

One of the women, Karmajong (Box 8.1) could not breastfeed her baby throughout the day as she had to wait until midnight to deliver her placenta.

> *I delivered her early in the morning at about 7:00, but I couldn't deliver my placenta until midnight. I couldn't breastfeed baby before this. (Karmajong, a 22 year old mother)*

Even the female community health volunteers initiated breastfeeding only after the expulsion of the placenta. During the participants recruitment process, one young local health volunteer stated that it took her about two hours to start breastfeeding after birth. She is a young volunteer with two babies and is relatively more educated than others in the communities. She also went through basic training related to the care of mothers and babies during and after pregnancy

It can be seen that most women are reluctant to breastfeed until they have had a shower and bathed their newborn. In addition, they are not ready to initiate breastfeeding before the burial of the placenta and cleaning of the birthing surface. Some also prefer to initiate breastfeeding after the baby has had a short nap after a bath.

During informal chats, it was revealed that further delay in breastfeeding occurred because the women were not allowed to wash their clothes or shower in the regular taps/wells. As women after birth are considered polluted (Chapter Seven, Section 7.3), they can take a shower only in selected taps/wells, which are usually located far from other taps/wells and can take ten minutes or even longer to reach. Some families helped by bringing water and allowed women to shower outside *Gotha*, particularly, during if childbirth occurred at night.

Avoiding colostrum is a common practice among mothers and their families. When Sita (Chapter Six, Box 6.21) lost her newborn due to diarrhoea and vomiting, she perceived that her baby's sickness was due to poor ingestion of her first milk (colostrum).

I think it is due to my first milk (colostrum). The nurse in the hospital told me to feed the first milk. But, I think it was not good for the baby, difficult to digest it. My baby vomited the same milk, and also had diarrhoea (Dudh Ukhelne and Chherne). (Sita, a 20 year old mother)

Likewise, Penghmu (Chapter Seven, Box 7.1) expressed her first milk following her mother's and neighbours' suggestions. Penghmu is a young girl aged 16. She lost her newborn on the first day after birth.

I was confused, what to do. My mother and other women told me to expel the first milk (colostrum). Then, I expelled it. (Penghmu, a 16 year old mother)

Young women have minimal support and guidance after birth as they have to remain in *Gotha* on their own [Chapter Seven, Section 7.3]. Young women also lack a basic knowledge about the methods and frequency of breastfeeding. They rely on their family members, in particular their mothers-in-law.

The problems arising during baby feeding such as inadequate supply of breast milk are usually believed to be related to unhappy *Dewata* (God) (Chapter Six, Section 6.2). As a result, the solutions to such problems are sought from faith healers rather than the health care providers. Some participants, especially in the *Lama* community, believe that babies start breastfeeding from the second or third day after birth. Dolma (Chapter Seven, Box 7.11) could not breastfeed the baby; her newborn baby died on the first day. Dolma's husband said:

Our baby died on the second day after birth. He didn't suck well. [They waited hoping that baby will suck]. Here, it is said that a baby drinks while in the womb. Therefore, some babies may not drink for up to three days. Our elders and neighbours told us that it is normal for many children not to feed on the breast for two to three days. (Dolma's husband, a 35 year old father)

In some families, it is identified that an inadequate supply of breastmilk has led them to pre-lacteal feeding. When Tengri (Chapter Six, Box 6.10) could not secrete her breastmilk, her family fed the newborn with pre-lacteal feed: a mixture of honey, *Chhyang* (fermented local alcohol) and roasted barley flour. Subsequently, the newborn died on the 27th day after birth.

My daughter-in-law's breast milk was not secreted for the first three days after birth. We bought cow's milk and mixed it with honey and Chhyang [local alcoholic beverage] to feed the grandson. However, the baby died on 27th day after birth. (Tengri's mother-in-law, a 67 year old woman)

8.2.2 Feeling Unsafe and Uncomfortable in Health Facilities, Freedom and Ease at Homebirths

The other issues affecting women's decisions regarding birth at home versus birth at health facilities are related to their perceptions of the lack of safety and comfort in health facilities. Women feel uncomfortable and disrespected during childbirth in the health facilities. They lack confidence in the providers' performance to assist during birth and treat their sick newborn babies. In addition, they do not feel safe about augmentation (use of oxytocin injection) of their labour.

Interviewees report experiences of fear of, and mistreatment from, service providers. They perceive providers' behaviour as controlling, and making them feel hopeless and fearful during childbirth. Those who attended a facility birth once, did not like to repeat this experience again. Hashakali (Chapter Six, Box 6.6) had a hospital birth during her second last pregnancy, but preferred not to go there for childbirth again. She is currently pregnant with her ninth child, and does not want to attend a health facility birth this time.

> *I gave birth to all my children at home except this daughter [the second to last birth]. Normally, at all homebirths, I had labour pain (Kaitha) for about two hours. But, in the hospital, it was longer, went for eight hours. I did not feel good at hospital. They [nurses] just throw us in bed. We can't even move our body; we have to remain in the same position, no movement. At home, we can move around; we can have tea; we can sit near the fire and get warmth. They shout at us, 'Do this Randi'. I was afraid at hospital. I was worried that if I died there, I wouldn't see my children and the neighbouring women around. At least we could die easily at home. I remembered my children very much when I was there [She smiles]. During the last birth, I was lucky; God helped me to deliver on the way. I didn't need to go to that hospital. This time, I will try to deliver at home until the last minute. I don't care about that rupee [the travel incentive to attend childbirth at a health facility, Rupees 1500 (about AUD 19)]. (Hashakali, a 25 year old mother)*

The lack of freedom while giving birth in health facilities is frequently reported. Kushumkali (Chapter Six, Box 6.17) reported her experience of being controlled; she felt uncomfortable and weak during the birth at hospital.

> *I was delivering at home always at my own pace. I felt very uncomfortable there. I don't know what these nurses (Doctorni) do there. They are always complaining, tell us to do this, to do that, move this way, move that way [body posture during childbirth],…many things…. They shout at us, as if we are kids. I didn't like it [She feels bored while recalling this experience]. (Kushumkali, a 31year old mother)*

Feelings of safety, comfort and respect are seen as being more important than the monetary incentive and the physical distance to a health facility. Both Hashakali and Kushumkalii live less than an hour's walk from the local hospital and within 20 minutes from the village community birthing centre. Yet, this made no difference to Hashakali in refusing to use the health care services.

The providers' mistreatment is the most commonly raised concern by women that has put birth at a health facility as a low preference for them. The low preference to attend a health facility for childbirth is also related to the low amount of incentive. Although the monetary incentive of 1,500 Nepalese rupees (about 19 AUD) (see Chapter Five, Section 5.3) is aimed at motivating women to give birth at a health facility, the amount of the incentive is perceived to be rather low. One study participant, a woman pregnant with her 10th child, who lives less than an hour's walking distance from the hospital and less than 20 minutes' walk to the local birthing centre, stated:

> *What to do with Rupees 1,500 [about 19 AUD]. This is a tiny amount. This is okay just for one small plate (Bila) of meat. The nurses are not good (Bichkiyeka). They shout at us. I can give birth by myself here [at home]. It is much better at home. (Punchamaya, a 35 year old mother)*

The familiar environment of home provides a much higher level of freedom to the women. Like the young women's experience described above, Sunita's mother-in-law perceived that women receive strength and courage while giving birth at home, and are ignored and frightened in hospital births. She does not believe in women saving babies by giving birth in a hospital.

> *I like my own home. If this soil tells you to die, it will do so whether you are at home or in hospital. I didn't really like giving birth in hospital. I saw many women here (in local hospital) and also in the city, you are just thrown in a bed. You don't get strength there. You feel hopeless, which is really bad. Here (at home), we make it ourselves whatever way (position) we want to lie on the ground, we feel more comfortable here. When I was in the city, I told my relative women there too, not to go to hospital. At home, you can walk around, go inside or come outside whenever you want. (Sunita's mother-in-law, a 65 year old woman)*

Sunita is a 20 year old woman, married at 17 and currently studying at grade 11. Her husband is studying a Bachelor's Degree. Sunita lost her newborn baby a year before on the third day of birth. Sunita's mother-in-law is a traditional birth attendant *(Sudeni)* in the village. **[Box 8.2]**

Women also feel uncomfortable attending pregnancy check-ups. Junamati (Chapter Seven, Box 7.3) felt anxious when the service provider shouted at her and did not clearly explain about her pregnancy.

> *They [nurses] shouted at me. I returned home twice without having a check-up. We don't know how to talk there (at health facility). We feel uncomfortable, and we are confused. They don't clearly tell us about our pregnancy and the baby's condition in the womb. (Junamati, a 25 year old mother)*

It is evident from Karmajong's story (Box 8.1) that women's feeling of being unsafe in health facilities is also affected by the lack of privacy and the language barrier between patients and health service providers.

> *I don't feel good to go there [in the health facility]. They make us lie down and tell us to take off our clothes. There are also other women standing nearby. I feel very uncomfortable. Also, I don't know how to speak well in Nepali language. They don't understand my dialect. (Karmajong, a 22 year old mother)*

Karmajong lives less than five minutes' walk from the local health facility, a birthing centre. However, she prefers not to go there because of privacy and the language barrier. Despite their family's support, other women like Laldevi (Chapter Six, Box 6.20) and Dolma (Chapter Seven, Box 7.10) felt reluctant to attend a birthing centre due to the lack of privacy during their pregnancy check-up and birth. Regarding the language, about half of the villagers in the second village speak *Bhotebhasa,* the local language. As is evident in Karmajong's story, women in the *Lama* community were uncomfortable when the nurse did not understand their dialect.

The sense of feeling unsafe in health facility births is also linked to the mothers' previous experience of not being able to save a previous baby. Birupa (Chapter Six, Box 6.3) went to a hospital to give birth with her first two pregnancies. After two losses (the first while giving birth at

hospital, the second baby died at home on the 26th day after the hospital birth), she was afraid to attend hospital during her most recent (third) pregnancy.

> *My previous two births were in hospital. Both times, I lost my babies. Therefore, I didn't like to go there last time. This baby (the third child) was born here [at home], and he is alive. (Birupa, a 19 year old mother)*

Women have doubts concerning the quality of care and the providers' competence when they lose babies during or after giving birth at a health facility. Birupa's husband had doubts concerning the providers' competence and also felt ignored at the hospital.

> *They don't care about us in the hospital. We are just ignored. And, you know, there are non-experienced health workers. I think they don't know much. (Birupa's husband, a 21 year old father)*

Currently, the couple have a newborn baby born at home. Both Birupa and her husband are educated people and Birupa's father-in-law is a local political leader.

Binita (Chapter Seven, Box 7.2) decided not to give birth at a hospital. She related the loss of her two babies to the birth at hospital. Her first baby was stillborn in a hospital, and the second baby was born in a hospital, but died later when hospitalised for pneumonia treatment. Binita also doubted the quality of care at the hospital when her baby's pneumonia did not improve even after admission.

> *I didn't like to go to hospital. I lost my two children there [first child was stillborn and the second became sick after birth]. We stayed over a month for the treatment of our second baby. Health workers said that our baby got pneumonia. It didn't improve, he died in hospital. We had to take him to the burial place directly from hospital. Last time [during her third pregnancy], I didn't like to give birth in hospital. Also, this time I will not go there, I will give birth at home. (Binita, a 20 year old mother)*

After two successive losses, during the third pregnancy, Binita and her husband were afraid to go to the hospital, and they were also blamed by their neighbours for their previous hospital births.

The lack of trust in hospitals is also seen in relation to management and treatment of sick newborns. In the same way as Binita losing her confidence during the treatment of her sick newborn, Sumitra's family also felt unsafe when the providers injected their newborn at several sites in his hand, attempting to put in an intravenous device to administer medication. The family discontinued the treatment after the first three days and went home despite the health provider's suggestion to stay in the hospital. Sumitra's grand mother-in-law commented:

> *They injected here and there [punctured many times in baby's arms] to that little newborn. There was blood from the injection sites. Baby's hand was swollen due to the injections. We did not feel good staying there. We brought the baby home. On the following day the baby died. (Sumitra's grand mother-in-law, a 68 year old woman)*

Sumita is a 19 year old girl, who studied up to grade 10, and got married at 16. Her husband is studying at grade 12. Sumitra lost her first baby two years ago on the fifth day after birth. She has another baby now. **[Box 8.3]**

Feeling unsafe about giving birth in a health facility is also related to the uncertainty about whether the augmentation in hospital birth causes the deaths of their babies. Ramkali's father-in-law (Chapter Seven, Box 7.3) had concerns about whether the augmentation (injection used to quicken labour) of his daughter-in-law's labour caused the death of their newborn soon after birth. After this, Ramkali last year gave birth at home.

> *The health workers said to bring one injection [Suhi: injection oxytocin] to quicken her labour (Kaitha). Then, I went to a drug seller to buy this. They gave it to my daughter-in-law. After this, she gave birth within two hours. The baby was born alive. But, shortly after, the newborn died. I was afraid there [had doubts about if something went wrong], and the daughter-in-law had also the same feeling. We didn't know what that injection (augmentation) did. After this, we decided not to attend the hospital for childbirth. She gave birth to this grandson here [at home]. The baby is alive and growing well. I think that the injection was not good for the baby. (Ramkali's father-in-law, a 61 year old man)*

Another example comes from Penghmu's family (Chapter Seven, Box 7.1). Penghmu delivered her baby during the eighth month of pregnancy. It was a pre-term birth *(*before *Hunemahina)*, and the baby died on the same day as it was born. Although Penghmu said she had never visited a health facility during her pregnancy, her husband and mother-in-law were not sure whether or not she had or if she had taken any medication that augmented her labour resulting in an early childbirth and consequent death. During the informal chats, it became very clear that many women did not feel safe about the medications obtained from the public sector; they were concerned about whether they were given expired drugs. Consequently, they believed that medications from private drug sellers were better, stronger and more effective. Some of them feared that the early losses in pregnancy, pre-term births and consequent deaths could be due to the medications obtained from the public sector health facilities.

As described in Chapter Six, the *Lama* people in particular, strongly believe that the *Dewata's* (God's) will affects the birth process and causes complication/sickness for the mother and baby. Therefore, taking a woman or a baby to a health facility is considered to make God unhappy. Such a belief also influences perceptions of safety regarding hospital births and seeking care from health facilities during a baby's sickness.

8.3 Context: Health Governance Failures in Delivering Care during Pregnancy and Childbirth

As already detailed in Chapter Five, Nepal introduced specific policy strategies concerning institutionalisation of newborn care up to primary health care level; mobilisation of Skilled Birth Attendants (SBA); expansion of birthing units to ensure 24-hour childbirth services in the rural

areas; availability and accessibility of round the clock basic and comprehensive care for mothers and newborns; and childbirth incentives and free maternity care to encourage women to give birth at health facilities. Yet, there are a range of health system failures hindering the delivery of basic care during pregnancy and birth. Issues particularly about rural workforce support; and lack of accountability and monitoring, emerged as key factors hindering access to pregnancy and childbirth services in the villages.

8.3.1   Health Workforce Support: the Work Environment for Skilled Birth Attendants

The lack of trust in the health service providers and the reported inefficiency of the health workforce can be better understood if one looks into the work environment and support given to the health service providers and, in particular to those who were posted to remote areas. Auxiliary nurse midwives, followed by staff nurses, comprise the major bulk of the Skilled Birth Attendants (SBAs) working in rural areas in Nepal. Nepal's national SBA policy (MOHP, 2006a) considers provision of care during pregnancy and birth as the key responsibilities of the SBAs. An enabling environment for these providers is therefore crucial to ensure good performance. Personal and family issues related to staff safety, security and loneliness; support from co-workers and the community; and availability of accommodation and basic amenities for living in the health facilities, emerged as the key factors concerning workforce practice in the villages.

Many factors are attributable to the lack of safety among nurses working in the rural areas. These include the local men's drinking habits, the lack of basic living amenities available such as safe quarters, water supply, communications and electricity in the health facilities. A local nurse from the *Lama* community explained that it is almost impossible for nurses to live and work in the villages.

> There are no quarters. I am living in my house. At least, I am a local. But, it is almost impossible to live and work here for the nurses coming from other villages or from outside the district. Because these are Bhote/Lama communities, they drink a lot of alcohol. Even if they are good, they get mad after drinking. So, you don't feel safe here. (Nurse from Lama community, HSP5)

During a post-interview chat, the above nurse (HSP5) explained that the drinking problem was also an issue with her male co-workers. It has made the health facility an uncomfortable place to work for nurses and to attend to their clients. During the fieldwork, I myself came across a drunk support staff (peon) and other health service workers at the workplace. I was stopped by drunk health service workers and other men who asked irrelevant questions.

Nurses therefore feel unsafe in the villages due to inappropriate behaviours and sexual harassment. A senior auxiliary nurse from the hospital described a recent incident of attempted rape by a local village teacher on another auxiliary nurse. After this incident, the auxiliary nurse took a job transfer from the village.

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You know, just a few months back, a new auxiliary nurse came here. She went to the village and rented a room in a villager's house near the health post. One day, a man broke into her room and attempted to rape her. Later, it was known that the man was a local school teacher from the village. …she was too scared to stay in the village so she took a transfer from the village after two months. (Senior Auxiliary Nurse Midwife, HCM3)

The nurses' safety concern related to living quarters in the health facility, and local community is also evident in a health worker's conversation, who suggested building a boundary wall around the health facility (Plate 8.1) to make the nurses feel safe and secure staying in their accommodation and providing 24-hour childbirth services.

It is difficult for a nurse to stay alone in the village. Particularly, they don't feel safe staying at night. We don't have a wall around this health post. At least building a wall around will ensure a feeling of safety for the auxiliary nurses. This will also make it clean and tidy inside the health facility premises. It will prevent village children from unnecessarily playing around here, and also prevent the cows and chickens from the villagers from entering into the health facility. (Auxiliary Health Worker, HSP7)

Lack of safe accommodation, often without basic amenities, has discouraged the nurses from staying in the health facilities. On observation, I noted that there was no accommodation in the first village birthing centre, and the accommodation provided to the nurses in the second village was a small room with no secure door or window. Neither of these accommodations facilities had a running water supply, nor any cooking facilities. The toilets were not functioning. The nurses had to fetch firewood to cook, and get buckets of water from a tap situated at a distance from the health facility. Because of very poor living conditions in the village, auxiliary nurses preferred to stay in the district hospital to have access to a somewhat better living accommodation and communications.

The lack of basic living facilities and the remoteness of the area make everyone feel lonely and

Plate 8.2 Health facility in the second village; Photo Credit: Author

worried. The villages lack reliable telephone and internet access. Low quality internet access and mobile phone networks are only available at the district hospital. I did not find a telephone in any of the village health facilities.[16]

In addition to poor living conditions and safety issues, working as a sole health worker in the village health facilities imposes a high workload on health providers. Nurses felt burned out due to the 24-hour working shifts and lack of any time for their families.

> *At least, here in the district hospital we have rotation. In the field, it is only you. You have to do night, morning, day and evening duties on your own. Yet, you don't get any additional incentive for it. Our family members are not happy with it. They frequently complain to us, 'You are doing 24-hour duty. How much are you earning then? There are school teachers who do just 10 [am] to 4 [pm] and earn the same. You don't have any spare time even when someone in our family is sick?'(Auxiliary Nurse Midwife, ANM 7)*

High level of expectations from nurses on the one hand and the lack of safety and basic living conditions on the other often create poor living and working conditions. One of the nurses shared her experience about resuscitating a newborn baby when she felt nervous and did not receive a co-worker's support.

> *We have to do everything on our own in the villages. I was alone in the health facility. After birth, the baby was asphyxiated. We didn't even have a bag and mask in the health facility. I tried mouth to mouth respiration, but couldn't save that baby. I was nervous; I requested my co-worker (auxiliary health worker), but he didn't support me. [She feels anxious alone].Then, I called a traditional birth attendant. At least, I didn't feel alone with this traditional birth attendant. Unfortunately, we couldn't save that baby. I still remember this today. These auxiliary health workers don't support us in childbirth even if we are alone. They do not consider it to be their job. (Auxiliary Nurse Midwife, HSP4)*

The poor support from male co-workers is found to be related to the national policy recognition of SBAs and non-SBAs. The policy identified auxiliary nurses as SBAs (MOHP, 2006a), but not other assistant health workers who are mostly males and in charge of the village health facilities. The SBA policy accredited auxiliary nurses and nurses as being skilled to attend pregnancy and birth. Before the policy was introduced, these allied male health workers were assumed to be the main local doctors attending births in the communities, and this was also their additional means of earning besides their regular pay. It was identified that villagers used to provide them with a new set of clothes, cash, and sometimes a goat or sheep as gifts on the occasion of births, more commonly when the newborn was a baby boy. After the introduction of the SBA policy, the nurses are increasingly burdened. Only nurses are considered responsible to ensure provision of pregnancy and childbirth services in the villages. Although the policy says skilled pregnancy and childbirth services are to be delivered with the enabling support of co-workers (those who are non-

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[16] During Nepal's major earthquake in 2015, I had to wait for three hours to make a call from the only telephone available in the second village. Yet this was not reliable; it frequently went on and off. Later, when I had no means of contact for three days after the earthquake, I had to walk seven hours to the district headquarter to inform my family and to update my PhD supervisors about the field situation. This situation is not unusual, and not just related to the earthquake.

SBAs), it is seen that the introduction of the SBA policy has been taken by some male health workers as an excuse for not getting involved in pregnancy and childbirth services. This has led male co-workers to flee from health facilities and run their own private drug stores. Interruption of pregnancy and childbirth services for any reasons, such as the absence of supplies and logistics for pregnancy and childbirth, are all left up to these nurses who do not have the authority to purchase drugs and logistics. The nurses demands are also not heard within the local health system.

Poor supply of basic needs from District Health Office and the hospital is an additional concern for most Auxiliary nurses and nurses. They frequently experience lack of stock of even basic supplies in the labour room.

> *They [allied male health workers and in-charge] don't listen. They don't listen to me even here at the district hospital. If there are not even simple medicines or other supplies, they don't care. There was no oxytocin in the labour room. I went to the [people] in-charge and the admin to repeatedly request them to supply it. I did not get the oxytocin for a few days. I wanted mothers not to die because of the lack of oxytocin. I carried it myself from the regional store. This system does not work here. This is the situation [feels sad]. Senior Auxiliary Nurse Midwife, HCM3)*

The DHO is supposed to be the main structure to supervise and manage authority to facilitate the implementation of programmes across the villages. Although nurses are expected to provide services, they are not coordinated with, or properly supported within the system.

8.3.2 Pregnancy and Childbirth in a Poorly Accountable Health System: Negligence, Lack of Monitoring and Corruption

Negligence, lack of monitoring system and corruption emerged as key factors hindering delivery of basic health care services during pregnancy and childbirth. Health facilities remained closed, only occasionally attended by health workers, or attended merely by peons, the non-skilled support staff. The health workers are frequently absent from the village health facilities; instead they are seen busy running their own private drug stores. The first section of this chapter (Section 8.1) described health care as being limited to the provision of tablets, and health services delivered from within the confines of health facilities only. Pregnant women were not able to access even basic health care services and supplies.

Women do not see any point in going to the health facilities (birthing centres) as the centres are frequently closed during week days. One woman, Aspura (Chapter Six, Box 6.5) explained:

> *There is no point in going to the health facility. I don't go. No one comes there. This is shut during the day. Every day is a holiday for these health workers. They just come once a month for immunisation. (Aspura, a 26 year old mother)*

Although the policy states that birthing centres provide a 24-hour service, they are often closed. In the first village, it is the peon (an orderly) who occasionally opens the birthing unit. Health workers are frequently absent, health facilities remain closed, and there is only a peon working as a birth

attendant. Women coming to the birthing centre end up giving birth in the front yard of the centre, or in the toilet, and are attended by non-skilled support staff (peon).

> *I have attended many women alone in this birthing centre. You know, I had to attend two women in the front yard [he points to the place in front] when they were at the last stage. I also delivered a woman in the toilet and another in the children's play room. I was not given the key to the labour room. Some women simply returned home. Later, the nurse (Madam) and the auxiliary health worker decided to give me the labour room key as well. Now, I can attend any woman. (Support Staff, HSP9)*

Junamati (Chapter Seven, Box 7.3) walked to the local birthing unit when she had intolerable labour pain. Unfortunately, she just had to return home in pain, as the birthing unit was closed:

> *When I had intolerable labour pain (Kaitha), I went to the birthing centre (Bhavanghar). It is just over there, takes only five minutes. However, it was closed. Neither could I meet the auxiliary health worker (Doctor) nor the nurse (Madam). A support staff member (peon) used to come occasionally. But, I didn't see even the peon that day. I had continuous pain. Then, we decided to go to the hospital. My brother-in-law looked around for a stretcher. But we didn't get that either as the only stretcher in the village was locked inside the birthing centre. (Junamati, a 25 year old mother)*

Plate 8.3 Birthing unit in the first village, padlocked during the day when I was in the village, Photo Credit: Author

Tenghmu in the second village had a similar story. Although the birthing unit is just a short distance away from her house, she could not find a single staff member when she had labour pains at night.

> *I had labour pain at night. There were no health workers in the health post. Where to go at night? They do not stay there. Neither the male health worker (Doctor) nor the nurse (Doctorni) stays there. They just occasionally show up in the health post. (Tenghmu, a 22 year old mother)*

Tenghmu is a 22 year old *Lama* girl, illiterate and married at 15. She has two baby girls. Last year, she lost her newborn on the second day after birth. Her husband is studying for a Bachelor's Degree, and her mother-in-law is a social mobiliser. **[Box 8.4]**

On paper, all positions are filled. Yet, health workers are not seen in their work place, in health facilities. I myself noticed that service providers usually did not stay in the health facilities for more than four hours (11am–3 pm) instead of a full day working hours of 9 am to 5 pm. This has created a further difficulty for women to attend health facilities.

It is identified that the service providers are present at village health facilities only towards the end of each month just for the sake of reporting their monthly health progress report for their pay release from the district.

> The [person] in-charge appears at the health post when it is time to send the monthly progress report to the district office. We have one in-charge (health assistant) of the health post, one village health worker, one auxiliary nurse and two auxiliary health workers. However, they are just there to count on paper. They do not come here. It is only me opening this health post. They are busy in their private drug stores and household work. (Support Staff, HSP6)

One of the local journalists also commented on health service providers' lack of responsibility towards public health facilities:

> There are about a dozen private drug stores. These are all run by the government health workers. They do not stay in the village heath posts. They receive monthly pay from the government. But, they are always seen busy in their drug stores. You know, it is too much here, even their wives who are lay persons, they are selling drugs. (Local Journalist, SH2)

Absence of staff from work is also common at the DHO level that is responsible for supervision and monitoring of village health facilities. The DHO is supposed to effectively mobilise and monitor village health facilities. The frequent turn-over and absence of a district level manager and medical officers has compromised the management and delivery of health services. It is already years since the district office has had a medical superintendent, the person in-charge of the district. Pregnancy and childbirth services are hit the hardest due to workforce absenteeism. The district hospital initiated Caesarean Section (CS) in 2013 with the help of a team of volunteer nurses and a gynaecologist from an International NGO. However, it was soon discontinued when the doctor and nurse supported by the INGO left the district. Also, during the fieldwork for this study (February to June, 2015), I met a gynaecologist and a nurse from the INGO who had been there for months to support the resumption of CS. However, the hospital could not resume CS by the end of this study fieldwork. Frequent turn-over and absence of chiefs and managers has not only affected delivery of basic services, the supports of I/NGOs is also not effectively mobilised.

At the hospital level, only one or two nurses are available at the work place. Some are reportedly on study leave; some are temporarily transferred *(Kaaj)* to regional and central level; and those on study/training leave did not return even after the leave was over. The maternity ward in the hospital is frequently handled by a single nurse with the support of some auxiliary nurse students.

> Only one staff member has to care for indoor patients as well as work in the labour room. There are very few staff available. This time, you can see these auxiliary nurse students.

Government policies recommend that women should be delivered only by an SBA (see Chapter Five, Section 5.3). However, it was identified that nearly half (25) of the total (53) births reported in the birthing centre (of the first village) during the last three years were attended by the support staff only. This birthing centre is located less than one hour's walking distance from the district hospital. It is managed by the local birthing centre management committee, and supported by a non-governmental organisation. Such negligence in the village birthing unit has not been monitored; in fact no one from the DHO has been to this village for the last two years to monitor this situation.

I haven't seen anyone from the district coming to guide us for the last two years. The chief of the District Health Office and two doctors came at the time of inaugurating this birthing unit three years ago. After this, once a doctor visited in the first year. Since then no one has come here to see us how we are doing. (Support Staff, HSP9)

The national policy (MOHP, 2013) outlines that women attending health facility births will receive a childbirth incentive as a transportation cost immediately upon their discharge. However, it is evident that women in the villages have not received it for more than two years after their births.

It is already two years since more than half of the women have had the incentive. It is not clear when the nurse (Madam) brings and distributes it to them. It is up to her. (Support Staff, HSP9)

This is a complicated scenario related to false reporting of health facility births and misuse of incentives. It is noted that health facilities have fabricated their records of facility births. I identified that 12 women in the first village reported by the birthing unit as health facility births were actually homebirths. The amount of childbirth incentive money to be released to a particular birthing unit is based on the number of reported health facility births. The motivation behind the data fabrication is to demand the childbirth incentive from the district and to misuse the incentive. I also had a chance to participate in a meeting at the DHO to discuss regulating the childbirth incentive. It appears that as a trick to misuse the childbirth incentive, the village health facilities even bypassed the district public health nurse, and reported (alleged) monthly facility birth records directly to the administration and account section in the DHO.

The monthly progress reports are also untrustworthy and it could be seen that these are not prepared seriously. These reports consist of reporting the status and activities about general health care including health care during pregnancy, childbirth and postnatal periods. Reports also include morbidity and mortality reports including stillbirths and neonatal deaths. As described in Chapter Four, there are discrepancies in reporting perinatal deaths in the villages and in the district register, and the deaths reported in the central department's annual reports. As a rule, the monthly report is to be prepared after a meeting of health volunteers and health workers in the villages. Health facilities are expected to reflect on the situation and set monthly goals, however the reporting

process in health facilities is found as being simply for the sake of releasing the monthly salaries of staff.

Misuse, mismanagement and delays are commonly reported in the construction, maintenance and delivery of health facilities. The construction of the birthing centre building in the second village had started three years prior to the fieldwork period (in 2011), and was completed in 2014. However, the handover was not done by the time of this field work (June 2015). Due to limited space until the handover, pregnancy check-ups and childbirth took place in a single room of the old building (Plate 8.3) where there is not enough space for two women. Likewise, the facility lacks even basic supplies such as the labour bed, running water, electricity and heaters or a placenta pit. Women coming for childbirth have to take their placenta back to dispose on their own. A local auxiliary nurse regrets the quality of care provided in the birthing centre.

> *It is discouraging here. We can't do much. We don't have labour beds. We have just got a mattress on the floor. I keep a plastic sheet over the mattress and deliver babies. We don't have even a placenta pit here. After birth, women have to take pads and placenta in a plastic bag to bury on their own. We have no electricity, no heater. We can't offer even a bed and a blanket to have a rest for 6/7 hours after birth. I think it is better for women to give birth at home than here. They can't get even a glass of water here. (Auxiliary Nurse Midwife, HSP8)*

Nurses frequently experience shortages of basic supplies while delivering care due to management negligence in procuring and supplying stocks. They run out of the basic supplies such as catgut, oxytocin, and even cord clamps.

> *She was bleeding, had a tear in the perineum. I couldn't even repair that tear. There was no suture in the institution. I had to refer that woman to the hospital. (Auxiliary Nurse Midwife, HSP3)*

Likewise, a senior nurse described running out of basic supplies such as cord clamps in the labour room at district hospital. She relates such a situation to the staff's lack of accountability and corruption in procurement and supply.

> *Look, even here at the district hospital, we are disappointed. It is a shame. We ran out of threads to tie baby's umbilical cord, no cord clamps. We made the threads from gauze. Only, yesterday, doctor [the in-charge]) brought cord clamps. I requested to make a purchase from the store section time and again. But they don't care about it. We won't be making any changes here until all staff are responsible for their duties. This system is corrupted because they are just making bills without purchasing. (Senior Auxiliary Nurse Midwife, HCM3)*

The planning and management of supplies in the district hospital and across the villages is controlled by the person in charge and the administration staff at the DHO. Nurses are not often consulted in planning for procurement and supply. During post interview chats, out of her frustration with the misuse of resource in supply and purchase, this nurse added that she would want national and international non-governmental agencies to directly provide supplies rather than funds.

Likewise, one of the local media persons explained the negligence of the district health system as a barrier in supplying equipment and other supplies to the village.

> *Equipment and the free essential drugs do not reach the health facilities in the villages. The equipment is rusting inside the district store. Some of the drugs expire in the store, or they are distributed to the nearby villages only. The district office says there is no money to cover the transportation cost to deliver the supplies. This is too much negligence here. (Local Journalist, SH3)*

During an informal chat, a local political leader looked apathetic about the negligence and corruption in supplies. He commented that equipment and drugs supplied from the central government are stolen before reaching the district office. At the village level, similar negligence and misuse was seen. I had a chance to observe a programme that aimed to provide packets of nutritious flour to the pregnant and postnatal women. It was clear that these packets were distributed only to the families residing near the local stores. A pile of packets with expired dates of use was found in the local stores, which were subsequently allowed to be taken by the locals to feed their cattle.

Lives of mothers and babies are trapped within the negligence of the system. A local media stakeholder described the story of a woman who lost her life at eighth months of pregnancy due to the absence of a medical officer in the district and the negligence of the local government which ignored the woman despite repeated requests.

> *The staff are corrupt. They are not sensitive about mothers' and babies' lives. The local government chief couldn't help to save a woman despite our repeated request to rescue her. She was eight months pregnant and in labour pain for three days. She could not deliver the baby. She had to lose her life because there was no medical officer at the district hospital to do an operation [Caesarean Section]. She was not rescued [by helicopter] from the centre even after our repeated calls. We informed the chief at the district level, and the central health department in Kathmandu about this. However, the district chief reported to the centre that it was a simple case, not an emergency. Both the woman and baby died. (Local Journalist, SH2)*

To summarise, the first theme (Section 8.1) described that health care has been perceived merely as distribution of tablets such as iron tablets, anti-worm tablets and Tetanus Toxoid injection. The health institutions are considered as the only platform to provide pregnancy, and childbirth services. In addition the policies' key priority to promote health facility births, perceived self-image of primary health care providers as being a medical doctor (a doctor in the villages) has affected their working behaviour. As per their self-image about being medical doctors they are considered as someone staying in a health facility, prescribing tablets, and using a stethoscope *(Ala).* This has shaped perceptions about health care as tablets and, facilities as the only health care delivery setting. Receiving health care has been at the mercy of these village 'doctors'. Community health workers, such as female community health volunteers, have been utilised merely to bring women to health facilities. Counselling, health education, and community participation for maternal and newborn care are considered less important jobs, and therefore often missed.

The second theme (Section 8.2), relates to policy recommendations on baby care and how they are perceived by the local communities. Immediate bathing is believed to be essential to make babies active, and to make them cry. Stillborn babies are also bathed to find out whether the baby is really alive; if the baby cries then it has life *(Paran).* There are anecdotal stories of apparently stillborn babies coming to life after being given a bath. Covering a newborn baby in clothes makes no sense to the women and their families, as newborn babies are considered too young to wear clothes. The women and their families consider the first breastmilk (colostrum) to be indigestible for the baby, and they feel that the appropriate time to initiate breastfeeding is after the birth of the placenta and after the mother and the newborn baby have been bathed. Some also feel it appropriate to breastfeed the baby after both mother and baby have had a little nap. The second section described women's experience of feeling unsafe, uncomfortable, and disrespected in a health facility during their pregnancy and childbirth. The women find providers controlling and shouting at them. They also lack trust in the providers in seeking treatment for their sick newborns. They do not want to continue with giving birth in health facilities with the apprehension it may be unsafe and may not save a baby. Such perceptions of fear related to health facility births are also related to their belief that a mother's and a baby's sickness or death is due to making *Dewata* (God*)* unhappy (Chapter Six, Section 6.2).

Finally, the third theme (Section 8.3), addressed the health workforce issues, such as workload, nurses' accommodation and their safety concerns, and lack of governance. Auxiliary nurses and nurses working in the rural villages are not supported in their work place either by their male co-workers or from the District Health Office. They do not even have basic support with living quarters. They often work in health facilities under conditions with no electricity, no communication facilities, and no running water supply. Over and above this, they feel unsafe due to men's uncontrolled drinking habits and inappropriate behaviour in the villages. Nor do they have any support from co-workers in the health facilities, not even during management of birth complications such as resuscitation of baby, retention of placenta and prolonged labour. Lack of monitoring, negligence within the system, and corruption has led to the frequent absence of health workers and mismanagement of basic supplies and logistics. This has hit delivery of pregnancy and childbirth services the hardest in the villages. Lives of mothers and babies are trapped in a failed health system with poor accountability. Health facilities are frequently closed, opening only for limited hours when unskilled non-medical support staff (such as a peon) attends to women in labour. Nurses experience lack of stock of even basic supplies such as cord clamps, basic drug to induce labour, and suturing needles. The recording and reporting of health facility births are grossly incomplete and unreliable. False reports are made in order to draw women's childbirth incentives.

8.4 Discussion

This study has shown that issues in relation to health governance contexts are vital in the utilisation and acceptance of health care services and community's perceptions on pregnancy care, childbirth and neonatal care.

The first theme in this chapter discussed the challenges caused by the solely medically-oriented primary health care system, health care perceived as purely the provision of medicines (*Tata)* and health facility premises as the only platform to deliver health care. The concept of primary health care as introduced in Alma Ata advocates a social model of health care (Lawn et al., 2008). In the primary health care approach, the focus shifts from ill health and hospital care to people and communities as resources for their health. Equity and justice, community participation and ownership, coordination and collaboration with multiple sectors are key principles underpinning the comprehensive primary health care model. Primary health care workers are expected to possess the knowledge of local socio-cultural contexts, work with the people in their communities, and are considered as the bridge between communities and health facilities (WHO, 1978). Mobilising and empowering local communities for behaviour change and health promotion are their key responsibilities. However, the present study reveals that underpinning values of primary health care, of a health worker, and the scope of primary health care are undermined. Health facilities have turned into occasionally opened stores to dispense tablets (rather than a health facility providing comprehensive primary health care), and primary health care workers have stayed with their own built-up self-image as a 'doctor' in health facilities, often distancing themselves from families and communities. This image is also transferred to the villagers, who in their ignorance and innocence regard all health care providers as 'doctors'. Prenatal care amounts to occasional supply of iron and deworming tablets, the antenatal and postnatal visits are mere ticking off of contacts in health facility registers, and a quality childbirth a mere slogan in policy. As well as the primary health care workers' false self-image as a doctor, the policy emphases predominantly on health facility births and mobilisation of childbirth incentives (see Chapter Five) have confined health care within health facility premises. Health workers and even female community health volunteers are reluctant to make community and home visits. This has led health workers to just wait for women to come to health facilities, although only a handful of women make health facility visits. The role of the health volunteers as a community mobiliser has reduced, they have been utilised simply to push women from communities towards health facilities.

Functioning community health is a foundation, and is vital for linking health facilities. All delivery settings: family, community/outreach and health facility are considered crucial to effectively contribute to improve perinatal survival (Bhutta et al., 2014; Darmstadt et al., 2005). The setting for maternal and neonatal care is not limited to health facility premises. Family and community settings are equally important, more so in high mortality and low resource settings. One clear message is

that one setting (delivery platform) cannot be negated in place of another; outreach/community care can no longer be negated with a focus limited to confines of health facility. Evidence suggests that family and community-based approaches are proven to reduce both stillbirths and neonatal deaths in low and middle income countries (Bang et al., 1999; Baqui et al., 2008; Kumar et al., 2008; Manandhar et al., 2004; O'Rourke et al., 1998; Persson et al., 2013). These include interventions such as participatory women's group mobilisation in Bolivia (O'Rourke et al., 1998), women's group and homebased neonatal care in India (Bang et al., 1999; Kumar et al., 2008), women's group mobilisation in Nepal (Manandhar et al., 2004), community-based newborn care package in Bangladesh (Baqui et al., 2008), and local stakeholders mobilisation through maternal and newborn health groups in Vietnam (Persson et al., 2013). The essence of these approaches is community mobilisation, engagement and empowerment for behaviour change and utilisation of maternal and child health services. The present study identifies that women and families are not informed and sensitised about maternal and neonatal health. There are no two way dialogues between health providers and the women even when women make health facility visits. Health workers consider education and counselling related jobs as less important compared to prescribing tablets. Health education or behavioural change approach is limited within health facility premises with the occasional distribution of leaflets to the women who are barely literate, and where reading is not a culture in the communities.

Encouraging community dialogues as Freire (2000) suggested through his 'Pedagogy of the Oppressed' could help to sensitise community groups, and this is the heart of family/community-based approaches discussed in maternal and newborn health. Freire suggests that the secret of dialogical approach is a facilitator who during facilitation process remains on an equal footing with community people, and becomes mindful of the local people' silence—people who may not even be able to raise their voice and concerns, and put forward their demands. This strategy is suggested to make people from the community conscientious and empower them, even when they are barely formally literate. In this case, the role of a facilitator or a change agent, that is health providers and health volunteers at primary health care level, should therefore be considered as a vital aspect of functioning community health. Such an approach facilitates dialogical interactions which can help to translate the essence of family/community-based maternal and newborn health approaches such as mobilisation of women's groups, stakeholder groups, and outreach and family/home based maternal and newborn care strategies.

Family/community health approach is even more crucial in the study region due to its high mortality burden (perinatal mortality >40 per thousand births) and a large proportion of homebirths (about three-quarters) (MOHP et al., 2012). National policies in Nepal (see Chapter Five) are described as being community-based, which acknowledge community-based approach as their value. The present study explores that, first, access to even a basic pregnancy, childbirth and postnatal care is trapped around the strategic tensions of home versus health facility (see Chapter Five). In

practice, health facility has been considered as the only delivery platform with home and community visits as mere slogans stated in policy documents. Out-reach clinics (ORC), female community health volunteers, Mothers' Group (MG) which are considered the foundation of the Nepalese community health/primary health care (DoHS, 2014; New ERA, 2007), remain neglected. These structures are underutilised; the focus is limited in distributing basic medicines and the system plays a passive rather than active role in service utilisation. The critical social mobiliser role of female community health volunteers has been limited to driving women towards health facilities. This driving role, but not a mobiliser/educator role, has been further encouraged by the childbirth incentive policy that provides about 19 AUD for a woman who attends health facility birth. Outreach Clinics which are considered as platforms to educate and sensitise communities have been reduced to 'a box of tablets' containing some pain medications, antacids, packets of oral rehydration solution (ORS) and medications for diarrhoea control and skin infections.

The second theme presented in this chapter is: quality of the health care: poor acceptance, feeling unsafe and uncomfortable in health facilities. The present study explores women's perception and experiences regarding childbirth and newborn care. Previous studies from Nepal have often discussed distance, no means of transport, and lack of transport fund as key barriers in seeking and utilising care during pregnancy and childbirth (Choulagai et al., 2013; Shah et al., 2015; Shrestha et al., 2012; Wagle et al., 2004). However, this study argues that women's and families' perceptions of unsafe, uncomfortable and disrespected childbirth in the health facilities are the key factors for their low preference and a continued poor uptake of even basic childbirth services from local health facilities. This argument is supported by the above discussion (in the first theme) that health care approach has been rather of a reductionist type; health care has been confined within the premises of health facility building, poor engagement with communities and tablet orientation. Despite policy acknowledgement of a socio-cultural approach, health care for women and children have been at the mercy of this prescriptive medical model. The national policies describe that access will be considered not just in terms of physical and financial access; it is described that by access, it will be also considered in terms of women's expectations, their dignity, trust and provider behaviour (MOHP, 2006a, 2006b, 2013). The national policies describe that a woman is to be understood not just as an individual, but in her socio-cultural contexts; maternal and newborn health programmes will be implemented in a human rights based approach respecting a woman's dignity, right to health care and privacy. The present study explored that such policy values are merely acknowledged in documents. In practice, women, who attended health facilities, felt controlled and mistreated by the service providers. Out of their bitter experiences in health facilities, some women said that they would rather accept their babies' deaths, and would continue giving birth at home. A majority of the women, even those living less than an hour's walking distance to health facilities, preferred not to repeat health facility births. In this regard, even the childbirth incentive, as provided for in the policies to motivate them to attend health facility birth

(MOHP, 2013) became a much less important factor for women's decision to come to health facility.

Women's perception about feeling unsafe in health facilities has emerged as another key factor reducing the uptake of maternal and child care services. This is an issue of women's and families' perception of safety and trust about health care. Trust is a relational concept, and is considered crucial in health care systems (Gilson, 2003). Provider and care seeker relationships and communication are at the heart of health systems. Studies have discussed that trust is an important factor for good personal relationship, seeking of health care, effectiveness of health care and desired behaviour change (Fugelli, 2001; Goold, 2002; Thom, Hall, & Pawlson, 2004). Regarding childbirth and care seeking for sick infants, a range of studies have indicated women's low trust related to their bad experience in health facilities, particularly of the providers' mistreatment (Kumbani et al., 2013; McMahon et al., 2014; Mselle, Moland, Mvungi, Evjen-Olsen, & Kohi, 2013; Phiri, Fylkesnes, Ruano, & Moland, 2014; Samuelsen et al., 2013). A recent study done in Bangladesh also found that women, particularly of low socio-economic group (slums of Dhaka) did not seek health care during birth and postnatal period due to their fear and distrust towards health facilities despite the availability of low or free modern maternity care in their close proximity (Akhter, 2015). Social and authoritative distance of health providers with the local women was identified as a key factor discouraging the women to seek health care from them. In the present study, safety and trust are related to predisposed ritual belief, supernatural belief about *Dewata* (God) and their expectations from health facilities including health provider, and health outcomes. First, the preference for health facility births does not align with the women's and families' cultural safety perceptions related to birth pollution (see Chapter Seven, Section 7.3) and belief that sickness and health are controlled by *Dewata's* will (see Chapter Six, Section 6.2). Second, safety is related to their expected quality of care at the health facility. Women and families do not believe that health facilities can prevent a child death; such belief has been reinforced further when they have prior experience of lost babies during or after a health facility birth. They have doubts on performance of providers, regarding pre-natal examination, augmentation of labour, and in treating sick newborns. They lack trust in quality of drugs from public sector and rather believe that drugs from private drug sellers are stronger and more effective.

Nepal is among a few developing countries to introduce early, a national strategy about neonatal health in 2004 (MOHP, 2004b). However, more than a decade after the introduction of the national strategy, the recommended basic newborn care about bathing, breastfeeding, and clothing are still not accepted by women and families in the mountainous villages. Immediate and exclusive breastfeeding within an hour, skin to skin contact, postponing bathing the baby for at least 24 hours after birth, and putting baby in clothes are recommended to keep the baby warm, protect from hypothermia and prevent infection (Costello et al., 2001). Such immediate care practices are considered even more crucial for premature and low birth weight babies who are more vulnerable

to hypothermia and infection. Infection is one of the persistently leading causes of neonatal deaths in developing countries (Lawn et al., 2014; Lawn et al., 2005), more so in weak health systems with high mortality settings as in the study region of Nepal. In Nepal, at national level, recent evidence shows that about 50% of newborn babies die due to infection (Dhakwa et al., 2014), which is likely to be even more in remote mountainous setting. It is estimated that simple newborn care interventions such as optimal and early initiation of breastfeeding can reduce 55 to 87% of neonatal deaths, and prevention and management of hypothermia can prevent 18 to 42% neonatal deaths (Darmstadt et al., 2005). However, the present study explores that this recommended care does not align with what women and families consider as culturally appropriate. The present study identifies that cold water bathe immediately after birth is perceived appropriate to wake up and establish a breathing in babies who are believed been lethargic *(Astadiyeka)* in the womb. Initiating breastfeeding is not considered appropriate until the mother delivers her placenta, buries it, and both she and her newborn take a bath. Wearing clothes for newborns is considered appropriate only when women and families feel certain about their survival which is perceived when babies start crawling. Such cultural beliefs are strongly rooted in people's everyday life to an extent that health volunteers themselves, as members of the community, follow traditional practices around newborn care rather than evidence-based policy recommendations. There are two points emerging: first, the importance of taking cultural determinants into considerations in policy formulation and implementation, and secondly, the quality of health workforce training modules is well-addressed to ensure community cultural issues. In this regard, it is crucial to ensure whether the evidence based messages have trickled down to women and families in communities, and whether the message has been customised to a local context. It is speculated that the results of trainings conducted up to the level of change agents, the health workers including health volunteers, have rarely reached, mobilised and engaged women and families in the study communities. This is explained by the declining essence of comprehensive primary health care approach in implementing maternal and newborn care interventions, limiting maternal and newborn health to a one-off vertical training package, often centrally planned without ensuring a functioning and strengthened local primary health care system.

The third theme presented in this chapter is about local health governance failures in providing pregnancy and childbirth services. Literature shows that there is a shift from generating epidemiological evidences on what, where and when of neonatal deaths and stillbirths (Lawn et al., 2011; Lawn et al., 2005) towards understanding health system constraints in delivering care (Dickson et al., 2014). Identifying and addressing the system constraints is crucial to accelerate the slow reduction of stillbirths and neonatal deaths in African and South Asian countries. The *BMC Pregnancy and Childbirth* published a series entitled 'Every Mother Every Newborn' in which bottlenecks in delivering essential newborn care interventions have been discussed (Dickson et al., 2015). With the experience of health professionals at country level workshops, the bottlenecks

have been categorised across elements of health systems (WHO, 2007b). Health service delivery, human resource management and financing are graded as the most commonly identified bottlenecks for poor access to and survival outcomes for mothers and their newborns in developing countries. The present study, with the experiences of women and families and frontline health workers at primary health care level of remote mountainous region of Nepal, adds that local health governance failures such as poorly accountable local health system (negligence, lack of monitoring), absence of health workers in their work place and lack of an enabling environment for SBAs emerged as key factors to compromise access to even basic pregnancy and childbirth services in the villages. The lives of mothers and babies are trapped in the complex context of workforce issues, negligence, corruption and mismanagement of health system supplies. It is not due to lack of technical, financial or human resources, it is due to the failures in local health governance which has strongly impacted access and delivery of even basic pregnancy and childbirth services in the study villages.

Nepal's national policies mention that every woman and newborn must have access to round the clock emergency obstetric and neonatal care (including blood transfusion, caesarean section, neonatal resuscitation) (DoHS, 2014; MOHP, 2004b, 2006b). Policies describe access to 24-hour childbirth services from Skilled Birth Attendants (MOHP, 2006a), free maternity care and childbirth incentives for women attending health facility births (MOHP, 2013). However, even a handful of women who attend health facilities in the villages, could not receive even a basic pregnancy and childbirth services. It is a consequence of local health governance failures: related to the workforce support and implementation of the SBA strategy, absenteeism of health providers, and the negligence, misuse of resources and corruption in the local health care system. Previous studies have primarily suggested the need of an integrated primary health care in general to improve maternal and newborn health in developing countries (Bhutta et al., 2008; Ekman, Pathmanathan, & Liljestrand). These studies mainly emphasised the linking of health facilities with community-based interventions, intersectoral coordination such as with education, income generation, women's awareness and empowerment. However, local health system accountability is barely discussed as a factor crucial to advance maternal and perinatal survival. As well as a focus on integration, the poorly accountable local health system provides a breeding ground for misuse of resources and negligence, and has therefore a substantial negative effect in provision of maternal and newborn health services at local level as seen in the villages studied for this study.

The lack of support to the nurses at local level, who are the main bulk of SBAs working in rural villages, emerged as a key factor in lack/discontinuation of childbirth services from health facilities. It is identified as a key factor for low retention and/or frequent absence of nurses in their work place. The SBA policy allocated a key responsibility on nurses and auxiliary nurses as skilled providers of pregnancy, childbirth and newborn care. However, the concerns and opinions of the nurses are little heard within the health system; they are poorly supported to ensure access to

basic equipment and drugs, low support from male co-workers and the health facility in-charge (who are mostly males). In addition, not having basic living support such as living quarters, running water, toilet, electricity and communication are the most common difficulties for a nurse to stay in village health facilities. Those working in the villages often do not receive monitoring supports from the District Health Office (DHO). It is explored that nurses feel unsafe to handle mother and newborns' complications alone in the villages, where women and families often contact health facilities at a late stage and with high expectations. Therefore, as well as the support from the local health system to create an enabling environment for nurses, the need for co-workers' collaboration at their work place is an important aspect for future policy and planning in the study settings.

The implementation contexts at local health facilities have negatively impacted on the effect of childbirth incentives. Voucher/Incentive schemes have been introduced in many developing countries to address disparity in service utilisation among the poor/disadvantaged (Bellows, Bellows, & Warren, 2011). Despite national policy recommendation to provide the childbirth incentive (monetary) immediately upon discharge (MOHP, 2013), women who attended health facility births have not received the incentive (monetary) for more than two years after birth. Also, it is identified that health facilities have fraudulently reported facility births data to misuse childbirth incentives. The incentive amount to a health facility is distributed based on the numbers of health facility births reported. In such a context, the incentives are rather seen to create false facility birth records without actually providing childbirth services from health facilities, thus breeding health system corruption. The effects of the voucher/incentive programmes to increase women's access to quality care, as some studies described (Bellows et al., 2011), are considerably less likely in such a health system context. Systematic review by Bellows et al. (2011) showed some positive outcomes in utilisation of childbirth and postnatal care in Bangladesh and Cambodia. The authors did not detail the reasons behind what made those positive outcomes. Two former studies from Nepal showed some progress in increasing health facility births, but a low impact in reducing neonatal mortality (Powell-Jackson & Hanson, 2012; Powell-Jackson et al., 2009). The authors explained that utilisation of services increased among women in the settlements with nearby health facilities; the effect still did not reach those most in need, the poor and most vulnerable segment of population. Lack of a wider policy communication in communities and a poor quality care in health facilities, was suggested as a reason for the low impact of the childbirth incentive. The present study adds that focus on implementation aspects at local level can help to reach the most in need. The women are less likely to benefit from such schemes due to the following three points: firstly, the incentive (monetary) created health workers' fraud in the local health system such as false childbirth records, not provided on time (upon discharge), and intentions to misuse; and secondly, a majority of the women still do not attend health facilities. As earlier discussed, they have a low preference for health facility births particularly due to local cultural beliefs, and uncomfortable and disrespected feelings due to provider mistreatment.

The health sector in general has been identified as one of the top sectors to be affected by corruption that includes different forms such as absenteeism (petty corruption), negligence and mismanagement in supplies and service delivery, misuse of resources in construction and maintenance work of health facility buildings (Lewis, 2006; Vian, 2008). Less corrupt government is identified as a significant protective determinant for improved infant, under-five and maternal survival (Muldoon et al., 2011). In the current study, in addition to misuse of incentives in health facilities, misuse and corruption regarding the basic supplies are commonly reported; drugs and equipment are stolen on the way during supply, remain expired and rotting in the district store. Whereas, as above discussed, nurses run out of basic supplies such as catgut, cord clamps and oxytocin in health facilities. These system failures show a complex context of accountability failures service delivery at district and local primary health care system level. The policy declaration about providing 24-hour skilled childbirth services through birthing units (MOHP, 2006b, 2013) remains as an empty slogan due to poorly functioning health facilities. Women do not see the point of going to health facilities because either they are closed, or there are mostly peons (orderlies) in these health facilities who are non-skilled support staff, not qualified even as a Traditional Birth Attendant. Health service providers only occasionally show up in health facilities, usually towards the end of a month when they need to report to the district for their monthly pay release. Quality care, 24-hour childbirth services, round the clock obstetric and neonatal care, and reaching every woman and every newborn are mere statements in policy documents.

The findings discussed in this chapter have strong policy and programmatic importance. These findings strongly suggest that having a long list of proven interventions alone is not enough to improve perinatal survival. Studies describe ranges of interventions along the continua from home to health facility, pregnancy to postnatal (Bhutta et al., 2014; Darmstadt et al., 2005), and national policies also describe these interventions to improve poor maternal and newborn survival (see Chapter Five). This study challenges the current community-based interventions in the essence of engaging and empowering families as essentially meant. Socio-cultural contexts have been undermined both in formulating and translating the policy values and strategies in the villages. The primary health care system in the study region has missed the collaboration with the age-old faith/traditional healing system (see Chapter Six, Section 6.2), and has overlooked the potential of success through family and community-based approaches. As discussed above, high mortality, a large proportion of homebirths, and the high prevalence of faith healing (Chapter Six, Section 6.2) in the villages strongly urge to revitalise community health/primary health care. It is speculated that missing primary health care approach could be one factor for the low impact of Nepal's newborn care package in the ten pilot districts (Paudel et al., 2013a). This could also explain the relatively poor progress seen in other areas of the country despite noted progress seen a decade ago in reducing newborn and perinatal mortality rates by the Makawanpur trial in Nepal (Manandhar et al., 2004). The large proportion of homebirths in the study region, and the women and babies' ritual

confinement (Chapter Seven, Section 7.3) strongly urge a culturally based community/primary health care approach in the study region.

Policy makers and programme implementers are suggested to reorient primary health care system towards an expanded view of socio-cultural system. Kleinman (1978) describes health system as an extended cultural system that constitutes professional (formal), folk (traditional healing system) and popular arena (family/domiciliary). Kleinman recommends viewing the health system as a conceptual model to understand how health and sickness are produced and responded to in a society. He adds that sickness is produced within a family context, and the first response to it is made within family. It is estimated that 70 to 90% of sickness episodes are managed within a family setting by self-care and by the use of traditional therapies. This becomes even more important to the present study as the care for mothers' and babies' sickness in the study villages are barely sought from health facilities; these are often left to local faith healers (Chapter Six, Section 6.2).

The World Health Organization Commission on Social Determinants of Health suggested redefining the role of health systems as health promoting systems (CSDH, 2008). The health system itself is considered be based on social determinants of health (SDH). The commission recommends that the health sector should take the stewardship role for action on SDH of health. Rather than making people passive recipients of medical treatment after sickness, empowering and engaging them to identify their needs and health promotive actions are considered central to the SDH approach. Internationally, the success of mobilising parents and parent groups have been tested by the 'Born Too Soon' movement that introduced pre-term birth as a key international policy agenda for reduction of neonatal death rates (Darmstadt et al., 2014). Mobilising and empowering parents and families is also one of the five key strategic activities outlined in the Every Newborn Action Plan (WHO, 2014c). Yet, in the present study villages, education and counselling related jobs are considered as poor jobs, of low esteem and less important by the service providers. As earlier discussed, supplying medicines is the only job valued by health providers. It is speculated that government's continuous efforts in maternal and newborn health related task shifting to assistant health service providers, the drug prescription authority, and the medicalisation of health volunteers in Nepal might have shaped their perceptions about and impacted on their job behaviour with a false image of a 'doctor'. In managing childhood illnesses in Nepal, the village health workers, including health volunteers, are given authority to prescribe selected antibiotics to sick children (Dawson et al., 2008; Khanal et al., 2011b). Tablets and capsules (Vitamins, anti-worm and Iron) have been the key in Nepal's community-based health programmes. The author believes this has devalued the core essence of community-based health care programmes from engaging and empowering communities to distributing tablets as the only valued goods of health care. This tablet only approach is much less likely to break the whirlpool of waiting for a fatal sickness (of mother and baby) to come; it is limited to treating sick newborns rather than engaging

and making women, families and communities aware of health promoting behaviour. For this, the primary health care system in these villages needs revitalisation. The essence as put forward by CSDH and the comprehensive primary health care approach is missing, and improvement in maternal and newborn health, which requires a whole system to function, is compromised.

The chapter strongly suggests that preventing stillbirths and neonatal deaths needs a whole new systems approach, not just attributing these deaths to intervention or to intervention packages. A problem, in this case stillbirths and neonatal deaths, is to be viewed as a part of a system, and emphasis should be given to understanding of the relationships, linkages, interactions and behaviours within the system. This aligns with 'systems thinking' which is proposed as a solution to accelerate health outcomes in global health agendas such as child and maternal health in low and middle income countries (De Savigny & Adam, 2009). System thinking is an approach that views delivery of health care and its outcome from a whole system approach, rather than a mere focus on specific set of interventions. The health governance failures explored in this study show a complex interrelated context of accountability failures in delivering health services. Inefficiency in delivery, and poor quality maternal and newborn health services due to poor accountability (poor responsibility of health service providers, lack of monitoring/supervision and reduced community participation in the rural health centres, poor coordination of government health centres within their own departments and with NGOs) are also found by a recent study from Bangladesh (Islam, 2016). In the present study, the issues surrounding work force support and poorly functioning health facilities strongly indicate accountability failures of local health systems towards health care and survival of mothers and their babies. I observed a complicit nexus among health facilities, District Health Office and political leaders. The bitter truth is that local political leaders keep quiet despite knowing such a reality of local health system. The policy values describing human right based approach and stating that survival is the right of every mother and every newborn (MOHP, 2004b, 2006b), is simply a statement on paper. Receiving even basic health care has been at the mercy of the service providers. The rural, disadvantaged and indigenous women and families in the mountains are not by themselves able to question these failures within the local health system. Therefore, this study suggests that approaches to increase local health systems' accountability are needed urgently to deliver health services, to reach every mother and newborn. Internationally, accountability in maternal and newborn health has been one of the key priorities, especially after the UN Commission on Information and Accountability for Women's and Children's Health (WHO, 2011a). The focus has been on measurement of the deaths and tracking of intervention coverage. From this study, I argue that accountability should not just be limited to tracking outcomes (deaths and program coverage) at national level, it is strongly imperative to make local health systems such as in this study region more responsible to deliver care for every mother and every newborn. Ensuring whether women and their newborns received a quality care should be a priority rather than a focus limited simply to pushing women towards a health facility and counting the health

facility contacts. Only then, when the policy values are translated in the field, no one, particularly the women and children from disadvantaged, remote and rural areas will be left out.

8.5 Conclusion

The local health systems are not prepared to ensure access to basic pregnancy, childbirths and postnatal care for mothers and babies. Relegating the essence of primary health care to the mere distribution of tablets (and other simple medicines), women's unsafe and uncomfortable experiences during childbirths in health facilities, culturally misaligned newborn care practices and failures in workforce management (including safety concerns of female health care workers), absenteeism, negligence and corruption in reporting, incentives and supply management have undermined health care in the villages. Lives of women and children have been compromised due to the poorly accountable local health system and poor consideration of socio-cultural factors in health service delivery. It is imperative to enforce basic standards in health facilities, and to sensitise nurses and health service providers about the right to health care, respect and cultural competency. In this regard, there is also a scope for clients' exit/satisfaction surveys, in-depth studies, and studies that uncover the nature of client provider relationship/communication. In-depth studies about how behaviour change/health educational approaches are implemented would be equally valuable to understand the knowledge transfer process from health service providers and volunteers to women and families in the communities.

The next chapter, Chapter Nine, is the last chapter of this thesis which draws on key highlights, study implications and potential areas for future research that can help to improve the ongoing poor perinatal survival in the mountainous villages.

KEY HIGHLIGHTS, STUDY IMPLICATIONS AND CONCLUSION

Poor perinatal survival in the mountainous region of Nepal reflects continued existence of age-old religio-cultural practices, and inequalities in access to health, information and social services. From a human rights perspective, this is a matter of injustice. Globally, almost 99% of perinatal deaths occur in developing countries (WHO, 2017a, 2017c), and the current trends estimate that it will take more than 100 years for a developing country to experience a similarly low level of perinatal mortality as a developed country is currently experiencing (Lawn et al., 2014; Lawn et al., 2016). In Nepal, it has been evident that perinatal mortality rates have remained high over the years. In particular, in the mountainous region of Nepal, perinatal mortality rates have been so high that they equal the highest rates recorded in the world, such as in Angola (UNICEF, 2015b). This has been happening despite some improvement in maternal and child health overall (MOHP et al., 2012; Paudel et al., 2013b). Additionally, only less than one half of all women seek basic antenatal, childbirth and postnatal services in Nepal, and this proportion is even much less in the mountainous region (MOHP et al., 2012). As stated by Marmot (CSDH, 2008, p.8) "It does not have to be this way and it is not right that it should be like this. Where systematic differences in health are judged to be avoidable by reasonable action they are, quite simply, unfair. It is this that we label health inequity. Putting right these inequities—the huge and remediable difference in health between and within countries—is a matter of social justice".

The present study was conducted in Nepal's mountainous region which provided an opportunity to examine social and cultural determinants of health and illness in an area experiencing high perinatal mortality rates. As outlined in the literature review, the majority of studies conducted in Nepal has captured an insight, mainly from urban and semi-urban areas with a principal focus on medical description and interpretation of perinatal survival. Evidence is sparse on the influence of socio-cultural and health service factors on perinatal mortality in the study area. This lack of evidence makes it difficult to inform national and regional policies and practices that are culturally appropriate, acceptable and equitable.

Earlier studies in Nepal identified epidemiological/bio-medical causes of perinatal deaths through perinatal verbal autopsies (Dhakwa et al., 2014; Khanal, Dawson, & Houston, 2011a; Manandhar et al., 2015; Manandhar et al., 2010), and survey based studies, such as National Demographic and Health Surveys identified bio-medical causes of perinatal deaths (MOHP, New ERA, & ICF International Inc., 2002, 2007; MOHP et al., 2012; Paudel et al., 2013b). At most, such studies described the distribution of perinatal deaths across different socio-demographic determinants. The

present study is aimed at examining and understanding the socio-cultural and health care contexts of perinatal mortality in the remote and rural mountainous villages of Nepal. The overall research question of this study was: 'Why is perinatal mortality so high in the mountainous region of Nepal?' followed by further exploratory questions: 'What factors (in socio-cultural and health care contexts) influence perinatal survival in the remote mountainous villages of Nepal and how do they interact?'

The area chosen for this study provided an opportunity to explore broader social contexts of poor perinatal survival. The data were collected by using in-depth qualitative interviews with a purposively selected sample of 42 women and their families who had gone through the experience of perinatal deaths within the last four years. The rich accounts of women were supplemented by other sources of data: interviews with 16 frontline health service providers (including two support staff, two health volunteers and one traditional healer) and four local stakeholders; field notes of informal conversations and observation in local health facilities; and the review reports of six policy documents related to perinatal survival in Nepal.

The views of women and their families and their experience about perinatal deaths, and factors hindering care seeking were the key aspects of investigation in this thesis. The study was framed within a qualitative methodological framework, abiding by the principles of valuing lay beliefs and perspectives, the women's and their families' experiences as authentic sources of knowledge; researcher's reflexivity in the research; and considering pregnancy, childbirth and postnatal care as women's and families' natural experiences. The bridge of social constructionism and critical theoretical perspectives shaped the methodological principles, data collection and analysis. Social justice, equity and human rights perspectives were used to explore contextual factors beyond just bio-medical causes of perinatal death such as infection, prematurity and intra-partum complications.

This study had four research objectives:

1. To explore women's and their family members' experiences and beliefs about perinatal sickness and deaths;
2. To examine the socio-cultural context of motherhood experiences (pregnancy and childbirth) and poor perinatal survival;
3. To examine health care delivery contexts of poor perinatal survival at a primary health care level; and
4. To consider the implications of the findings for health policy development and implementation in rural mountain villages

The first, second and the third objectives were addressed and elucidated respectively in Chapters Six, Seven and Eight that discussed field findings. The fourth objective was addressed in the discussion sections of these chapters and is addressed in Chapter Nine. Section 9.1 provides brief

highlights of the findings, which have been discussed at length in the previous chapters. The key implications and recommendations for further research are provided in Section 9.2 with a conclusion to the thesis in Section 9.3.

9.1 Poor Perinatal Survival: A Consequence of Religio-cultural Beliefs, Gender-related Cultural Contexts, and Health System Failures

This study explained that religio-cultural beliefs, gender-related cultural contexts and health governance failures are significant contributors to the high perinatal mortality rates in the study areas. Drawing on the previous chapters, this section presents the key highlights of the study.

Fatalistic Beliefs About, and Acceptance of Perinatal Sickness and Deaths

This study found that perinatal deaths occur in a context that early lives in pregnancies and during early postnatal period are given minimal importance and priority. The loss of a baby was considered by women and their families as a generational continuum that occurred to everyone in their natal and in-law families. Under a backdrop of people's acceptance of, and fatalism towards perinatal illnesses and deaths, the participants in this study put little value on stillborn foetuses and neonatal deaths, because deaths of such young lives were not considered as deaths of real persons. Not counting the young lives as real persons arises out of religio-cultural beliefs and rituals that do not consider perinatal deaths as a socially significant issue. The *Dewata* (God) was the predominant factor in causing sickness or health, and perinatal deaths were rationalised and accepted as *Karma* (past deeds), fate or destiny. Thus perinatal deaths were not considered a matter for discussion, reporting and reflecting on in these communities.

Gendered Social Constructs of Motherhood and Poor Perinatal Survival

Secondly, in this study, the gendered cultural context emerged as a strong driving factor perpetuating poor perinatal survival in the villages. The gendered constructions contributing to high perinatal mortality—**girl** settlement *(Gharbar)*; position of **a daughter-in-law** in an intra-familial context; and the ritual of observing pollution about **a mother and her baby** during and after birth were the highlights.

Settling a girl's home *(Gharbar)* is an underlying factor (motive) behind repeated perinatal losses in the villages. Such a motive has led women and families to continue with child marriages in defiance of the law against child marriage (Maharjan et al., 2012). This motive has perpetuated a vicious loop of child marriage, early and repeated pregnancies, baby losses and neglect (in case of the birth of a baby girl). A young adolescent girl is viewed to maximise her chances of having surviving babies, preferably baby boys by early marriage and repeated pregnancies. Motherhood is seen to cement a woman's fragile relationship with her husband, and her position as an insider in the in-laws' family. There is no previous study in Nepal exploring the family and community

contexts in relation to girl settlement *(Gharbar)* and its link to poor health and survival of young mothers and their babies.

A major factor explored is around the power relationships and status of women. The study identified that the pregnancy and childbirth experiences of the women were influenced by the low position of daughters-in-law in intra-familial dynamics. The patrilocal and extended family system is a cultural norm in these villages, as in other parts of Nepal. Husbands are barely expected to be involved in matters related to pregnancy and childbirth. The mothers-in-law of the pregnant women mostly exert a dominant, controlling role and have a significant impact on the care and support within the family and in accessing pregnancy and childbirth services from health facilities. But, they often do not fulfil their roles in providing care and support. In such a context, pregnancy and childbirth are taken as 'just natural events', which has relegated them to mundane state. Pregnant women often suffer from work-related exhaustion and falls, leading to births in farmland, on the way to or while in the forest, and hence an increased chance of death.

This study also confirmed the gendered religious construction of childbirth as a polluted event leading the mother to give birth with no support and her confinement in the *Gotha* (cowshed) during birth and postnatal period to keep the pollution away from the main part of the house. To abide by this norm of birth pollution is to perform a religious duty, and to make their *Dewata* (God) happy. Seclusion and confinement after birth are prevalent in other parts of Nepal, among both the Hindu and Muslim communities (Sharma et al., 2016), and in other South Asian countries such as in India (Bandyopadhyay, 2009) and Bangladesh (Darmstadt et al., 2006; Tarafder & Sultan, 2014). However, postnatal seclusion and confinement are observed even more strongly in the study villages. One of the peculiar findings of this study, which no other studies have pointed out, is that the mother is considered more polluted when it is a baby girl, thus requiring a longer postnatal confinement.

Medical/epidemiological evidence suggests that the time around birth and the immediate postnatal period is the most critical time for the prevention of the largest proportion of perinatal deaths (Lawn et al., 2014; Lawn et al., 2016). Hence, it is highly recommended to seek skilled attendance at birth, and where possible to give birth in health facilities. In addition to being far from a health facility and its available services, the place of delivery chosen for the birthing women in these villages is a corner/side of the *Gotha* (cowshed), on the ground floor of the house, which is far from appropriate for an event like childbirth. However, women feel culturally safe about themselves and their babies when they abide by the norms of ritual pollution, a fact also pointed by a previous study from Nepal (Kaphle et al, 2013). The present study further explored that the rituals surrounding birth pollution are aggravated by a lack of space in the main part of the house and the absence of basic amenities inside the house, such as water supply and toilet. These factors

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provide the families with a rationale for choosing the cowshed as the appropriate place for delivery, and a place to be confined in, following the birth of a child.

Poor Perinatal Survival in the Local Health Service Delivery Contexts: Declining Essence of Primary Health Care and Health Governance Failures

The delivery of maternal and newborn health services is affected by minimal focus on empowerment and engagement. The primary health centres were found to be lacking in the core principles of primary health care (WHO, 1978), namely: community engagement and empowerment in implementing maternal and newborn health interventions. *The Lancet* series on preventing stillbirths and neonatal deaths (*The Lancet*, 2005, 2011, 2014, 2016) provided a long list of interventions at family/community level aimed at increasing awareness and creating demand. Women and their families in the study villages were not given opportunities to learn or develop their knowledge to enlighten and empower themselves to negotiate resources, and to have authority over matters related to their health and survival during pregnancy and childbirth. Such an essence of the family and community interventions has remained a low policy focus, and appeared to be further neglected in practice. Existing national policies in Nepal (see Chapter Five) emphasise a shift from communities towards health facility births with monetary incentives used simply to persuade women to attend health facilities for the birth of their babies.

It is clear that the health care system has not been able to cater for the needs of women during pregnancy and childbirth. Normally, the health service centres were seen by the study participants merely as places for dispensing of 'tablets' (basic medicines), restricting their scope to the occasional distribution of iron tablets, Tetanus Toxoid (TT) immunisation and deworming tablets to pregnant women. Because of this, the present study explored the reason why the local health providers including female community health volunteers and a peon (an orderly) in the health facility accepted the false image of being addressed as a 'doctor' (see Chapter Eight, Section 8.1) even when none of them is a qualified medical doctor. These health care providers focus their work solely on prescribing tablets. Health care remains predominantly confined within health care facility premises. Community engagement, education and counselling are considered less important jobs. The acceptance of the false 'doctor' image has created a social distance between the community and the providers, and has been a key factor in eroding the essence of primary health care (Rohde et al., 2008; WHO, 1978), in terms of mobilisation, engagement and empowerment of women and families in the study regions.

Health services offered to women are unsafe, uncomfortable and disrespectful. Because of the mistreatment and controlling attitude of nurses, some women preferred to risk dying during childbirth at home rather than having a health-care-assisted birth in the health facilities. Homebirths in familiar environment and at their own pace, were considered more natural, and seen to give freedom and encouragement to women. There is a lack of privacy, and basic amenities in health

facilities, such as no waiting area, no drinking water, no toilet with running water, no washroom and no cafeteria for women and their visitors. The lack of feeling safe in health facilities is also related to the belief in *Dewata* (God) as a factor in health and sickness, and the ritual pollution about childbirth. As discussed earlier in this thesis, women feel safe to give birth in a *Gotha* so that they are not polluting their house, and are not displeasing their *Dewata*.

Newborn care recommended by health facilities are not acceptable practices to the village women. This study demonstrated that women's low preference to attend a health facility is also related to their perceptions about immediate newborn care. Homebirths allowed new mothers the freedom to implement what they perceived appropriate care practices during and after birth (for both mother and baby). Their perceptions about appropriate immediate newborn care were different from the care recommended by health facilities (DoHS, 2015; FHD, 2013). Feeding the newborn with colostrum was not practised as it was considered indigestible by the newborn baby. Early initiation of breastfeeding within one hour was not practised as it was believed that the appropriate time to initiate breastfeeding is after the delivery and burial of the placenta, and after the mother and baby have had their bath. Bathing the newborn with cold water immediately after birth was seen important to awake up the newborn baby and establish its breathing, who are considered lethargic *(Astadiyeko)* in the mother's womb. Clothes for babies, as the national guideline suggested— woollen caps, trousers and socks *(Bhoto topi moja)* (DoHS, 2015; FHD, 2013), did not make any sense to the people of these communities. They preferred to postpone buying clothes and dressing babies until they were confident of their babies' survival.

Negligence and lack of accountability is exhibited by the broader health care delivery system. National policy commitments to provide 24-hour childbirth service through birthing centres (FHD, 2013; MOHP, 2006b), and commitment to provide round the clock emergency obstetric care to every woman in need (DoHS, 2014), are far from the reality in the study villages. Women intending to attend a health facility for childbirth often found the health facility closed, even during daytime working hours. Health facilities were in operation only on an occasional basis during weekdays, usually for not more than four hours a day and mainly run by non-medical support staff, locally known as a peon (an orderly). This situation in the health facilities reflects negligence and the lack of accountability in the health system, which is associated with low workforce support, especially for skilled birth attendants (SBAs), lack of effective supervision and negligence and corruption within the health system.

Besides a lack of support at workplace and supply problems, high expectations from the village women and families in local health facilities (birthing centre) has made the lonely SBA (auxiliary nurse/nurse) in the study villages feel even more unsafe. This lack of safe feeling is because the SBAs are often called upon to attend childbirth at late stages of complications as a last resort, and

because the birthing women refuse being referred to a higher level health facility. Such circumstances compel the SBAs to often flee from the village health facilities.

The health system suffers from poorly functioning supervision and monitoring. Monthly progress reports including records of livebirths, stillbirths and neonatal deaths are not prepared with due diligence and accuracy. Instead, reports and records about intervention coverage and perinatal deaths were frequently found to be false. There was an over reporting of facility births and missing records of perinatal deaths in the study villages (Chapter Four, Section 4.5 and Chapter Eight, Section 8.3). The health facilities falsified the data about facility births in order to misuse the childbirth incentive, and women were paid the incentive until more than two years after giving birth in a health facility. The purpose of the incentive is to motivate women to attend childbirths at a health facility, and to ensure skilled care to tackle high perinatal mortality. Based on the findings of this study, it can be said that it is not just the lack of resources, and not even remoteness of the villages, but it is also a lack of accountability in basic health service delivery at the local health facilities that can account for the failures of health governance and failures to ensure access to quality health care in the villages. The right to receive basic health care will not be realised for every woman and every child simply by focussing on measuring results or tracking intervention coverage at the national level. Without first ensuring responsive local health governance, the mere focus on counting deaths and tracking coverage at national level is more likely to be unreliable and misleading. Such a focus on only 'numbers' will put aside the importance of ensuring whether women and families in the villages have actually accessed the needed health care. Paying attention to accountability of the local health system is even more imperative as it has been found internationally that accountability in maternal and newborn health has been driven mainly towards counting every death, and tracking intervention coverage at a country level (Darmstadt et al., 2014; UNICEF and WHO, 2015). There is a low focus on making the local health systems accountable to deliver health care consequently women and families at the grassroots are yet to experience the changes as aimed in national and international policies.

Interactions of religious interpretations, gendered constructions and health service factors have driven the continuation of poor perinatal survival in the study regions. High perinatal deaths and fatalistic beliefs have shaped the local people's fertility behaviour, especially as they do not feel certain about their baby's survival until s/he is able to crawl/walk. Aversion to family planning, especially the use of vasectomy is linked to their faith in *Dewata* (God) and is considered to go against God's will, and increases the fear of sickness or earlier death. The use of contraceptives by women in the villages is influenced also by other factors, which are mostly linked to the unfriendly behaviour of service providers, lack of proper counselling, and issues of client privacy in local health facilities, all of which have further undermined even a basic access to temporary means of contraception. Similarly, the gendered constructions (the intra-familial context and the ritual pollution) offer no help to a young mother, and often prevent her from accessing even the basic

health care for herself and her newborn. On the other hand, the contexts of local health governance failures reinforce the fatalistic religio-cultural beliefs of the women and their families. Women are discouraged from going to the local health facilities, who have no way other than to return home without getting care as the health facilities are either shut during the day or let the women return with a negative experience of not feeling respected and comfortable. Such a context offers the women no way than to rely on faith healers and ultimately continue to accept perinatal deaths as their Karma, fate and destiny.

9.2 Implications of the study

The findings of this study have several implications, both for policy and for further research.

9.2.1 Implications for Policy: Using a Socio-cultural Lens through Participatory Approach to Policy Development

Prioritising community/home based service strategy in policy making: In Nepal, although policies related to perinatal survival have acknowledged the importance of social determinants of health, the discourse in policy is predominantly swayed by medical and epidemiological evidence about what causes mothers' and babies' sickness and how they can be treated. As highlighted earlier, the main emphasis regarding childbirth is given to a shift of practice from 'home' to 'health facility' either through ensuring availability of Skilled Birth Attendants in institutional settings or by giving women a monetary incentive to travel to attend health facilities (see Chapter Five). However, as found in this study, the current emphasis only on health facility based service strategy will prevent about three-quarters of indigenous, poor, less educated women who still give birth at home (DoHS, 2014) and barely attend health facilities for any sickness. Policies and programmes should therefore strongly encourage community and home based models of service delivery, which is even more important due to the poor and fragile referral system in the mountainous areas.

Enhancing the role of health system beyond a medical system, and inform policies with local evidence about socio-cultural contexts: As reported earlier, this study has found that Nepal's policies are overwhelmingly medically directed, and the contents of the policies have a strong focus on complications and sickness management. It is seen that matters of maternal and child survival have been overly emphasised as medical event, and the implications of such emphasis are that the events of pregnancy, birth and care of a newborn baby are viewed only in a medical context, ignoring the very important non-medical contexts in which maternal and child survival occur. Mothers and newborns are attended to only after they become sick or suffer from complications. Policies embracing health system beyond a medical system, medical evidence and medical care are strongly recommended. The remote and rural areas as those in Nepal where women and families continue to utilise family and community networks and resources such as traditional therapies using faith healers, have their own socio-cultural interpretation of sickness and deaths. National policies should take a stewardship role to reorient health care systems to the

socio-cultural contexts in which the vulnerabilities to sickness and complications arise. Considering the concept of WHO's recommendation of a health system as a social determinant (CSDH, 2008) can help to develop policies that give attention to reducing exposure to factors that cause ill health, or reduce vulnerabilities to health damaging conditions rather than a predominant focus only on treatment after sickness. The policy makers of national health systems could also benefit from the views of Kleinman (1978) about health systems. Kleinman described health systems as extended cultural systems including domiciliary (popular) and folk sectors besides a formal health care /medical sector. Kleinman made a noteworthy point for policy makers and managers that over three-quarters of diseases or sicknesses are produced and responded to by popular and folk sectors of a health system. Owing to the predominance of faith healing in the study region, it is likely that even a greater proportion of diseases or sicknesses are responded to at home and by the folk sector.

Besides medical/epidemiological evidence, which have predominantly guided Nepal's health policies, it would be imperative for the policy guidelines or operational strategies to be informed by in-depth qualitative studies and evaluations that provide insights about local contexts. Local evidence of the contexts can help to produce policies, which can effectively contribute to tailor health care delivery to the local socio-cultural aspects. In this regard, it is suggested that lay knowledge be given a due place to inform national policies. Popay's ideas about lay knowledge could offer useful insights into how public health policies could be benefitted from them (Popay et al., 2003; Popay et al., 1998). Lay beliefs are not just taken passively as individuals' beliefs, but as knowledge that can challenge the experts' understanding and help make programmes contextual and equitable (Popay et al., 2003). Popay described that lay knowledge provides a relationship between socio-cultural contexts and experience of illness. It informs what people do and why they do in a particular way. In this way, lay knowledge can help a policy maker or a provider to understand what matters to women's and families' social world, which in turn becomes useful to tailor policies and programmes accordingly.

Involving managers and service providers in policy-making: The Nepalese health policy documents revealed that policy formulation is based on collaboration among the central level stakeholders, mainly among the health/medical experts from government and non-governmental sectors (see Chapter Five). The policies lacked feedback from those at the implementation/operational level, such as from district level health officials. One of the key reasons why the acknowledged policy values are less likely to be implemented is the lack of involvement of frontline health workers or policy implementers, called 'street level bureaucrats' (Lipsky, 2010). Lack of involvement of these frontline health workers is likely to result in policies that are not informed of the dilemmas that these frontline health workers face, and the interests of local people, which these frontline health workers are most familiar with in their day to day practice. The policies (discussed in Chapter Five) are conveyed merely as hearsay knowledge to health care managers

and providers at district level. They are not adequately informed about the intent and values of the policies and how they are going to implement them. Therefore, it is recommended that the policy development process involves service providers, so that their problems are understood and that programmes are available for them to use appropriately to address the health issues relevant to them. This will not only provide valuable feedback into the policies during their formation but will also increase the chances of diffusing the policy values at the implementation level, legitimise the policies and ensure a greater accountability to implement them.

Encouraging women's, parents' and local communities' voice in policy making: It is suggested that the voice of women, parents and communities be incorporated into policy development and priority setting. Listening to communities' voice and views is essential to adapt health professionals' (experts') medically oriented strategies to the expectations and circumstances that people face in the rural and remote villages. The power of parents' voice to prevent neonatal deaths, especially the deaths of premature babies is evident by the 'Born Too Soon' movement (Darmstadt et al., 2014; March of Dimes, PMNCH, Save the Children, & WHO, 2012). The movement galvanised parents' voices and established prematurity as an international agenda item to focus on reducing neonatal mortality. The European Foundation for the Care of their Newborn Infants represents more than 30 groups of parents across European countries; 'The Home for Premature Babies' in China has over 400,000 families with pre-term birth as its' members. These parents' groups became grassroots voices for visibility, political attention and governments', other partners' and other parents' actions on pre-term births (March of Dimes et al., 2012). Owing to the invisibility of perinatal deaths, which as this study found were not even considered as deaths of individuals, it would be imperative to introduce similar parents' groups as change agents in the study regions. The focus of the national policies in developing countries, such as Nepal should be to galvanise parents, women and communities rather than only passively supplying them with medical solutions after the onset of complications or sickness. The networks of health facility committees (health workers and community representatives), women's/mothers' groups or any parents' groups could be effectively utilised. This could be a great leap in practising collective policy making and a simultaneous policy communication rather than limiting policy as a job mainly of technical experts' working groups at the central level.

9.2.2 Enhancing Family and Community Engagement in Maternal and Newborn Health Programme Implementation

This study strongly suggests family and community engagement in maternal and newborn health programmes implementation. As stated earlier, about three-quarters of women in the study villages still give birth at home. Therefore, a strong focus on family and community-based strategies is required. The available long list or packages of interventions alone (Bhutta et al., 2005; Bhutta et al., 2014; Bhutta et al., 2011; Darmstadt et al., 2005) would not accelerate the reduction of perinatal mortality in such communities unless family and community-based strategies reinforce

engagement and empowerment of women and families for awareness, and creation of demand for skilled care. This study confirms that it is critical to enhance active engagement of families and communities in developing appropriate programmes, resources and services in order to address the high prevalence of perinatal deaths.

Revitalising comprehensive primary health care approach at local health systems: The present study highlighted that primary health care has been relegated to supplying tablets (medicines) to communities. This shrinking of the primary health care approach has disengaged the health facilities from local communities, thus ignoring the critical role of contextual factors in providing care. The local health system needs to be reoriented to implement the essence of primary health care (WHO, 1978). Primary health care is not merely a structure or a health facility, it is an approach to bring health care closer to families and communities, and to mobilise them as key stakeholders for their own health. The programmes, though referred to as 'community-based', are seen moving away from the purpose of engaging and empowering families and communities to promote health and prevent sicknesses.

Strengthening dialogical approach of health education and community mobilisation: This study explored that perinatal deaths and sickness are religio-culturally constructed as God's will, every day (ordinary) occurrences, results of *Karma*, fate or destiny. Discourse about behaviour change education should not just be based on medical causes of perinatal deaths, namely infection, complication of prematurity, and intrapartum complications (asphyxia) (Bhutta et al., 2014; Lawn et al., 2014; Lawn et al., 2016; Lawn et al., 2005). To make them effective and engaging, educational programmes need to take lay beliefs and experiences into consideration. This will not only inform policies, it will also be crucial for programme managers and service providers at primary health care level to get an insight into lay constructions about perinatal death and sickness. Otherwise, the professional discourse that reiterates the preventability of 99% of perinatal deaths is not likely to be realised in these communities. Owing to the acceptance of, and fatalistic views about perinatal deaths, it is imperative to initiate a meaningful partnership with faith healers and religious leaders in order to reverse the trend of poor perinatal survival at primary health care level in the region.

Family and community engagement is also essential to increase the acceptance of the current interventions such as the recommended immediate newborn care practices about breastfeeding, bathing, and clothing (Costello et al., 2001; MOHP, 2004b) which are culturally unacceptable, thus contributing to the low attendance at health care facilities during childbirth. The power to make dialogue by the women and families in the study villages is further inhibited by the professional distance created by their acceptance of the false image of a 'doctor' assumed by the orderlies and female community health volunteers. Acceptance by the women of this false image has prompted these primary health care workers and orderlies to pretend as someone of a higher social status,

which inhibits them from seeking an active engagement with the community. Clearly, the poor, illiterate and disadvantaged women and families are barely able to raise their voices and concerns about health care. It is necessary to implement education/behaviour change, not by just giving out brochures, and giving instructions after the onset of sickness or complications, but by continuously engaging with the community. Currently, the interaction between an individual and a healthcare provider consists merely of instructions about taking tablets or occasionally giving out educational brochures with a typical message about 'when to come to the health facility?' which are unlikely to be read by the women who are barely literate. Health education/behaviour change needs to be informed by what and how women and families perceive and experience sickness and death of their babies and the reasons behind their perceptions.

Freire's 'Pedagogy of the Oppressed' could offer some insight about engagement (Freire, 2000). Applying Freire's concept of dialogical approach, it can be identified that enabling a community dialogue process could help to understand the factors that are hindering the access to services, so that appropriate community-based services can be developed for women to use during pregnancy and childbirth. According to Freire's concept, individuals and communities could be liberated only by conscientisation (translation of a Portuguese term meaning consciousness raising), such as in this case about making the women aware of why they are continuously losing their babies, for which a meaningful engagement is critical. Freire highlights the partnership between a facilitator and an individual/community as the secret of the dialogical process in which both parties are on an equal plane, and not in a giver and receiver relationship. According to Freire, individuals or communities are not passive recipients, rather, they are considered to be capable of actively solving their problems. In this process, both the facilitator and individuals/communities become learning partners. Freire (2000) also raises a note of caution with the 'culture of silence' as a major impediment that can especially bar the poor/disadvantaged or oppressed groups from becoming open to dialogues and communication which can make programmes/facilitators willing to allow such groups to openly raise their voices and concerns. Hence, engagement is not simply a matter of calling the programmes as 'community-based' (as Nepal's policy documents do), rather they should ensure active engagement with every woman, family and community.

9.2.3 Health Workforce Training

Training of health workers/SBAs as social workers and partners in pregnancy and childbirth: The policy guidelines discussed earlier in this thesis are oriented mainly on transferring medical skills to health workers such as applying standard algorithms of managing infections and birth complications. The role of skilled birth attendants is seen only as a medical care provider rather than training and mobilising them as those who not only assist women with complications and newborn sickness, but also act as someone who understands and empowers women and make them feel proud and comfortable during childbirth. In this context, training of health workers/SBAs about cultural and sociological determinants of perinatal health is pivotal. This is

particularly important when the national policies have a focus on utilising professional health workers rather than traditional birth attendants (TBAs). Although TBAs have been proven ineffective to manage pregnancy complications and help reduce mortalities, it cannot be denied that they are trusted providers who are close to the women in the communities, know the women's cultural needs and preferences, and become partners in supporting women to give birth. The introduction of SBAs through Nepal's health policies is a step in the right direction so far as the provision of skilled birth attendants is concerned, but that is not sufficient to meet the socio-cultural traditions of local people. Therefore, it is essential to build and strengthen the socio-cultural competencies of the SBAs so that in the local socio-cultural context, birthing traditions and baby care are medically safe as well as culturally accepted. The SBAs should also be encouraged to work in partnership with the local TBAs. Interventions incorporating partnerships between midwives and TBAs introduced in Indonesia have been proven to be effective (Hermawan, 2016). The TBAs attend birth together with midwives, fulfil emotional and cultural needs of the birthing women, refer pregnant mothers to health facilities and provide postnatal services in the communities.

Orienting health workers and SBAs about right to health care, respect and dignity of women and their babies: As discussed earlier in this thesis, this study found that women felt unsafe, uncomfortable and disrespected in health facilities. It is therefore imperative to enforce basic standards in health facilities, and to sensitise the nurses and health service providers to the clients' right to health care, dignity and cultural feelings.

Training service providers about faith/religion and spirituality in health care: This study showed that traditional healing therapy, such as calling a faith healer, and praying to Gods and Goddesses during sickness are age-old options for the people in the study areas. Such practices have prevented people from seeking modern health care for a mother during pregnancy and childbirth, and during a baby's illness, simply because they wait for divine intervention to prevent deaths. In the event a death does occur, these people continue to accept such deaths attributing them to their religio-cultural beliefs in *Karma* (past deeds), *Bhagya* (fate) and *Lekhanta* (destiny). In fact, such constructions are considered as misconceptions because these are only popular conceptions rather than scriptural ones (Krishan, 1997; Prabhupada, 1972). Such misconceptions ingrained among the people due to their lack of awareness that diseases may be prevented or cured and deaths may be prevented with proper medical care. The lack of awareness is, at least in part due to an ineffective health care system that focusses only on supplying drugs and logistics rather than educating people to promote health and remove their false beliefs. As discussed in Chapter Six, the notion of '*Karma*' is an art and practice to raise awareness of people, empower them and instil in them a power to have self-control over the realms of *Karma*: thoughts, speech and physical actions to protect them from any misdeeds (Krishan, 1997; Prabhupada, 1972). The notion of *Dewata* (God) appears as a moral construct just to discipline one until s/he is not aware of the essence of *Karma*. Training health service providers about such an understanding of local

religio-cultural beliefs would most likely begin a genuine collaboration with faith/religious leaders and help develop programmes that enlighten people from religio-cultural misconceptions. This way, one can help respect the local culture, and at the same time enable women and families to benefit from modern health care.

Training all health workers about religio-cultural faiths could provide an improved understanding of religio-cultural contexts within which women and their families live. There is a growing realisation of incorporating spirituality in medicine/health care (McCormick & Min, 2014; Sorajjakool et al., 2010) to address patients' religiosity. As the findings in this study indicate, the curriculum of health providers including doctors, nurses, midwives and health workers should be revised to include topics on religio-cultural issues in health in specific communities. In addition, partnerships with faith/traditional healers could also help to ensure a culturally appropriate and respectful primary care services and increase the acceptance of health care.

9.2.4 Integration of Health and Social Policies

Implementing and assessing maternal and newborn health programmes using a gender approach along the continuum (adolescence, pregnancy, childbirth and postnatal):
Literature has predominantly described perinatal survival as a bio-medical construction—identifying perinatal death as a marker of quality of medical care around childbirth (de Bernis et al., 2016; Dickson et al., 2015; WHO, 2014b). However, this study highlights that gendered constructions in the continuum have been underlying forces to perpetuate perinatal deaths in the villages. Beginning with **an adolescent girl**, this study showed that the construction of girl settlement *(Gharbar)* which is related to child marriage, early and repeated childbearing, son preference and marriage survival of a girl/woman, emerged as a vulnerability to ongoing poor perinatal survival in the study areas. Further, this study found that the voice of **a pregnant mother (a daughter-in-law)** remains unheard, without any power to make reproductive and health care decisions. Similarly, this study showed that **a birthing mother and a newborn** are considered impure leading the woman to give birth unaided and remain confined in *Gotha* (cowshed) during her postnatal days. The vertical type of technical health programme packages or the long list of interventions alone as discussed in policy and literature are less likely to address the ongoing vulnerabilities in which women live their daily lives. Therefore, it is vital to consider a gender approach along the continuum of pre-pregnancy to postnatal to advance perinatal survival in the study regions. Use of a gender approach along the continuum of pre-pregnancy to postnatal would guide current programmes to sustainably contribute to improving poor perinatal survival—both stillbirths and neonatal deaths, rather than having an explicit focus only on saving babies after livebirths (the newborns) as current policies do (see Chapter Five). It would be useful to address the biased gender norms, relations, roles and responsibilities that become pronounced during adolescence, as a daughter-in-law and as a woman during birth and postnatal period.

The report of the World Health Organisation's Commission on Social Determinants of Health (CSDH, 2008) and the gender analysis guidelines of the Liverpool School of Tropical Medicine Gender and Health Group (LSTM, 1999) offer some insights about a gender approach in health. The CSDH has considered gender as one of the key social determinants of health, as a social position that arises out of socio-economic and cultural contexts (CSDH, 2008). Gender influences health and survival of a woman herself and her baby either through uptake of nutrition (feeding patterns) across a life cycle, or by compromising access to health care (CSDH, 2008). The Liverpool School of Tropical Medicine (LSTM) Gender and Health Group suggests examining and addressing gender issues across three layers: gendered norms, beliefs and values; gendered roles and responsibilities, and access to resources and decision making. Gender is a social construct that includes expectations from men and women—their roles, positions and relations which are often unequal and hierarchical (LSTM, 1999). Applying the gender analysis concept of the LSTM Gender and Health Group could provide insights to policy makers and programme implementers to develop, implement and assess maternal and newborn health programmes that do not just focus in describing mortality, morbidity or utilisation outcomes. Rather, such programmes are suggested to go beyond a pattern of illness/health outcomes, and to focus on understanding what leads to the unequal distribution of the outcomes, and in identifying and addressing gender relations that produce vulnerability to ill health. This thesis recommends that gender in the context of these villages should not be limited only to the distinction between newborn baby girls and baby boys, but as discussed earlier, it should consider the implications of gendered constructions before, during and after birth for the survival of the baby in pregnancy (foetus) and after birth (newborn). Irrespective of the sex of a baby, it should be necessary to view poor perinatal survival in its gendered cultural context, as evident in the present study. It is not about the sex of a newborn or that of a foetus, it is more about the unequal gender relations, roles and responsibilities which stem most prominently when a girl is an adolescent, when she is a daughter-in-law, and when she is a birthing and postnatal mother, all of which have been driving factors of the continuing perinatal deaths.

Some specific implications from this study which highlight the need for integrating health with social policies include:

- It was seen that child marriages, births and deaths of babies were hardly ever registered, thus masking the actual burden of death in the communities. Policy makers and programme managers should be aware of such under-reporting and the reasons thereof in order to ensure that every birth and death is counted. Local health facilities could collaborate with the local government, women's development offices, local schools and colleges to educate young girls and boys regarding prevention of child marriages. Inter-sectoral efforts through different settings: schools, health facilities, parents' groups, and faith/religious groups may be useful to

change the current notion of girl settlement *(Gharbar)* to prevent child marriages, and early and repeated childbearing.

- An intervention such as birth preparedness was practically non-existent as pregnancy and births were considered day to day, ordinary events. Programmes need to focus on the creation of an enabling environment for the young mothers within a family and make pregnancy and childbirth valued events.

- The study highlights that daughters-in-law were the lowest within the hierarchy based intra-familial power dynamics. As such, they were not able to decide on any matter including their pregnancy and childbirth. Therefore, in the context of these study areas, it is imperative for programme implementers to consider that educating or transferring knowledge to only young mothers (daughters-in-law) could be less effective in terms of behavioural change. In the family hierarchy in these villages, the mothers-in-law want their daughters-in-law to submit to whatever control they (the mothers-in-law) want to exercise. Therefore, the suggested education/educational interventions could be perceived as a challenge to their authority by the mothers-in-law they want, thus and make them even more controlling and hostile. Understanding such intra-familial contexts is, therefore vital for leveraging the effectiveness of family and community-based interventions.

- Gendered position of men in the study villages disengages them from matters relating to pregnancy and childbirth, but it is critical to encourage them to participate in such matters. Although male participation is mentioned in Nepalese policies, it barely exists in the study villages. The absence of male participation is against one of the key strategies of Every Newborn Action Plan (WHO, 2014c) to mobilise men to end preventable stillbirths and neonatal deaths. Male participation has long been encouraged in reproductive health (Bloom et al., 2001; Piet-Pelon et al., 1999). In Africa and Asia in particular, it is crucial that men should be involved in their wives' pregnancy and obstetric care and use of family planning to prevent unintended births so that the wives can have access to such services at health facilities (WHO, 2007c). Therefore, as mentioned at the beginning, it is crucial to engage men in the study areas to promote family planning ensure that pregnancy and childbirth are valued and women are supported during these special events of their lives.

- This study has revealed that the concept of ritual pollution has not only subjected young women to give birth in *Gotha* (cowshed) without anyone to assist them, but it has also prevented appropriate postnatal care for the mothers and their newborn. These unaided births in *Gotha* are unacceptable, particularly when the policies provide for skilled birth attendance because evidence suggests that childbirth and the immediate postnatal period are the most

critical times to prevent the largest number of perinatal deaths (Dickson et al., 2015; Lawn et al., 2014). In this regard, the present study strongly recommends that policy and programmes should consider the local context of a birthing woman and her newborn, and encourage home based births attended by skilled birth attendants.

Integrating maternal and newborn health programmes with daily living contexts (housing, sanitation, water supply): The findings of this study imply that policies and programs of the health sector to improve perinatal survival should be integrated with multiple sectors. Poor perinatal survival is linked to housing—size, space, and basic amenities. Small house sizes with no spare rooms cited as the reasons for choosing the *Gotha* (cowshed) as the place of delivery and postnatal stay for mother and baby. There are accounts of women in advanced pregnancies who fell down and lost their babies while climbing the difficult and unsafe ladders to the main living areas of the house (see Chapter Seven, Section 7.3). A stronger collaboration with the water and sanitation, and housing sectors is essential to ensure that these communities have access to basic and safe living conditions.

In addition, I do not deny that a lack of addressing the high prevalence of poverty, food insecurity, and illiteracy of women in the study region, are likely to perpetuate gendered stereotypes and even more unfavourable circumstances for ongoing poor perinatal survival. Therefore, a whole-of-government approach (WHO, 2014d) is required to tackle the problem. Such an approach considers population health and equity as outcomes of multi-sectoral policy collaboration and therefore prioritises 'health in all' policies.

9.2.5 Accountability Lens at Local Health Systems Level

This study explored significant policy practice gaps in providing basic pregnancy and childbirth services in the region. The policy statement about providing 24-hour skilled childbirth services through birthing units (MOHP, 2006b, 2013) remains an empty slogan.

This study strongly advocates that the health governance failures observed in the study areas (See Chapter Eight, Section 8.3) are mainly due to a poorly responsive local health system that breeds corruption in different forms such as absenteeism in workplace (petty corruption), misuse of childbirth incentives to negligence in management of supplies and service delivery. The health sector has been identified as one of the top sectors with corruption (Lewis, 2006; Vian, 2008). A less corrupt government is deemed as a protective factor for improved maternal and infant survival (Muldoon et al., 2011). In this study, the complicit nexus (See Chapter Eight, Section 8.4) between service providers in the villages, District Health Office, and local politicians has been a factor to contributing to corruption and poorly accountable attitudes of the local health system. This nexus poses a serious threat perpetuating a continuously disadvantaged position regarding utilisation of modern health care for village women and families, thus helping to reinforce the fatalistic views

about sickness and deaths in the study regions. Such a nexus has been a barrier in making the local health system accountable to deliver health services in the study areas.

The poor and illiterate women and families, in addition to having to return from a health facility without service (as health facilities are closed during the day), also find it hard to raise their demand to access 24-hour childbirth services. The women are not empowered to demand health care as their right; therefore, they are not able to make the health providers accountable. This is due to information asymmetry between providers and the clients, which is identified as a common reason to put the clients in a weak position so that they are not able to demand accountability from the health system (Brinkerhoff, 2003). In this case, the extent of asymmetry should be more pronounced because whatever basic health care the barely literate women receive, is at the mercy of the health providers.

As discussed earlier in this thesis, without the local health system becoming more accountable, the national/international policy focus on counting every perinatal death and tracking coverage of interventions (UNICEF and WHO, 2015), is likely to be simply a national report of unreliable numbers. Firstly, it is highly unlikely that the reported or recorded number of perinatal deaths at sub-national levels would represent a true picture of the actual number of perinatal deaths, as evident by the discrepancy between the number of perinatal deaths identified through interviews in this study and that recorded in the local health centres (see Chapter Four, Section 4.3.3). Secondly, on the other hand, it is seen that service utilisation, such as facility births, are over-reported in order to falsely claim childbirth incentives for misuse by the local health staff (see Chapter Eight, Section 8.4). The antenatal and postnatal check-ups in health facility are more likely to be 'contacts' ticked off in the maternal and child health registers without necessarily providing quality care to the women and babies. Therefore, taking accountability beyond simply measuring the numbers and facts at national health systems to ensuring whether every woman and newborn has received health care at sub-national level at primary health care centres is an urgent task. Only then, can it help address the existing failures related to workforce support, absenteeism and supply management, and help translate policy values such as 'rights' and 'equity' into practice.

Insights to improve health system accountability can be obtained from Brinkerhoff (2003), who described accountability as a system-wide perspective. The main purpose of accountability is to improve health system performance by ensuring efficient, effective and equitable service delivery through answerability and sanctions. An accountable health system can be ensured by reducing abuse of authorities and resources, and by assuring compliance with procedures and standards. Brinkerhoff described a range of actors in health system, such as Ministry of Health, service providers, funding agencies, NGOs, users/patients, health facility committee/boards having accountability roles. Identifying these actors, and knowing to whom they are accountable could be a starting point to address the accountability failures in the health system. In addition, Brinkerhoff

suggests that specific measures could be developed by using an accountability mapping tool to analyse the complex inter-relations of accountable actors, both on the supply and demand sides. Brinkerhoff recommends an accountability matrix exercise that gives a hint of how accountable health systems are in terms of capacity to supply and respond to sanctions, and the capacity to demand and impose sanctions. A recent study by Gurung (2016) in Nepal provides some insights on how accountability problems could be addressed at local primary health care level. Gurung emphasised the citizen's voice as a key to demanding accountability at the local health care level in Nepal. Factors at individual (patient/client), service provider and broader health system levels are found to affect citizens' voices, which ultimately reduces accountability of the local primary health care system. Besides increasing the citizen's voice at local level, it is suggested that policy makers at the national health system level need to seek alternatives to address the complicit nexus between providers, politicians and district health office where accountability failures are likely to remain ongoing due to the culture of protecting each other's weaknesses without enforcing any sanctions. It is to be noted that such a context is likely to flourish due to the weak position of the poor and illiterate women and families in the study region where receiving even basic health care has been at the mercy of the service providers.

9.2.6 Limitations of the study

This study has been limited in scope in examining the socio-cultural and health care contexts of perinatal survival. Although the thesis recognises sex-selective abortion as a factor linked to circumstances contributing to the likelihood of poor perinatal survival, this has not been discussed in detail owing to possible over stretching of the study topic beyond the scope of this thesis. The issue of sex-selective abortion warrants a separate detailed investigation.

Likewise, this thesis does not examine maternal deaths though many such deaths are likely to have arisen from the socio-cultural contexts that are similar to those of the perinatal deaths analysed in this thesis.

The study also has limitations related to language barriers and member check i.e. participants' validation of the transcripts (See Chapter Three, Section 3.8). Additional methodological limitations are identified in relevant sections of Chapter Three. As a conclusive note, as this study employed a qualitative methodological approach, the application of findings is specific mainly to the study region in Nepal, the rural mountain villages. However, general inferences could be drawn from the present study, particularly about the impact of religio-cultural interpretations, gender and motherhood, and health service delivery contexts in perinatal survival and applied to other similar settings in Nepal and South Asian countries which are grappling with high perinatal mortality. The potential of conceptual generalisability of the present study findings can be visualised through their contribution to knowledge about the influence of religio-cultural beliefs in shaping people's behaviour. A range of studies, both from other regions of Nepal (Deo et al., 2015; Matsuyama &

Moji, 2008; Subba, 2015) and from other South Asian countries (Kalim et al., 2009; Kayani et al., 2012; Singh et al., 2013b; Winch et al., 2005) have shown the importance of recognising the significance of local religio-cultural beliefs in influencing people's behaviour. Similarly a range of studies describe the prevalence and impact of gendered constructions surrounding child marriage and son preference throughout Nepal (Brunson, 2010b; Maharjan et al., 2012; Subba, 2015; Suwal, 2001) and other South Asian countries (Almond et al., 2013; Arnold et al., 1998; Barot, 2012; Kishor, 1993; Pande et al., 2006; Pörtner, 2015). Poorly functioning health system is recognised as a common factor in South Asian as well as African countries (Dickson et al., 2015; Dickson et al., 2014) undermining access to health care in maternal and child health. The policy context of perinatal survival in Nepal presented in Chapter Five is aimed to help policy makers and managers to see whether the study findings can be of use throughout Nepal. The experience of perinatal deaths as described by the women and families in the study villages are more likely to be the experience throughout the mountainous region and other areas of Nepal. The study participants from the *Lama* and *Khasan* communities, selected for this study are typical of the mountainous regions throughout Nepal. *Lama* is an indigenous ethnic group that shares some similar features with other indigenous ethnic groups such as *Manangi, Bhote, Thakali, Sherpa, Rai, Gurung, Kirati and Tamang* residing in the mountains and upper hilly regions, who are together referred to as *Tibeto-Burman*, or of *Mongoloid feature*. The *Khas/an* group of participants in this study comprises a range of ethnic groups from both the lower *(Dalit)* and upper castes *(Brahmin and Kshetri),* which are common ethnic groups throughout the country. The study field context described in Chapter Four of this thesis provides the detail of participants' socio-cultural life and livelihood, which provides readers with a reference to whether the findings could be useful throughout mountainous regions and other areas of Nepal, and elsewhere. Some of the inferences from this study could be also utilised in low resource and high mortality contexts of the other developing countries beyond South Asia, such as those from the African region.

9.2.7 Future Studies

Based on the findings of this study, this thesis indicates a range of areas for future studies that would help to understand and contribute to the efforts of improving poor perinatal survival in the mountainous areas of Nepal.

- First, as this study strongly suggested building collaboration with traditional healers, faith and religious leaders, it would be imperative to simultaneously plan this as an intervention trial to develop an effective and scalable model of collaboration and partnership to improve perinatal health at primary health care level. Such a trial could be a multi-group intervention trial, linking traditional birth attendants, women's groups, religious/faith healers and local primary health care facilities. Interventions, such as partnership of midwives and traditional birth attendants (Hermawan, 2016; Stollak et al., 2016) and women's groups (Baqui et al., 2009; Kumar et al., 2008; Manandhar et al., 2004) and stakeholders' groups (Persson et al., 2013) have been

found effective in different settings in the developing world. It is speculated that planning such interventions could be effective to revitalise primary health care and mobilise parents, women and communities and to raise their voices to end ongoing stillbirths, maternal deaths and neonatal deaths in the communities.

- Second, this study identified a total lack of men's involvement in pregnancy and childbirth related matters, which exacerbated the helplessness of their wives, the daughters-in-law in the extended family settings of the present study, who were left at the mercy of their strong mothers-in-law. It would be therefore important to examine whether Nepal's current women's groups (the Mothers' Group), and female community health volunteers (New ERA, 2007) have reinforced gender stereotypes regarding care of mothers and babies in the isolated communities as only women's responsibilities. Men are neither expected nor allowed to stay with their wives during labour, both at home and at health facilities. It would be imperative to plan studies to demonstrate the effects of running men's group education classes (when their wives are pregnant), and men's involvement (accompanying and staying) during labour. Such studies could be helpful to increase the value of pregnancy and birth, and to help plan birth preparedness.

- Third, the present study found delivery of health care at local health centres transformed to only prescription of medicinal tablets (pills) and their distribution, a 'tablet orientation', with a poor engagement with families and communities. The educational roles and related activities of the health centres were often given low priority. It would be imperative to plan in-depth studies about how behaviour change/health educational approaches are implemented at primary health care level. Such studies would be valuable in understanding the knowledge transfer process from health service providers to the women and families in the communities. Discourse analysis that involves real-time observation of provider and client (women) interactions could uncover additional insights.

- Fourth, this thesis strongly indicates that home based models of providing childbirth and postnatal care through Skilled Birth Attendants could be more effective and less costly approaches to reach every mother and every newborn in the mountainous villages. This study showed that providing the tiny cash incentive to attend health facility birth is less motivating even to the women living close to health facilities. Rather, the cash incentive was found to tempt providers to over-reporting in facility birth records to misuse the incentive. The study found that women would have been more satisfied by having a SBA who could understand their culture and tradition, and support them to have safe and satisfying births. Having a SBA attending homebirths and postnatal visits could also help to understand the women in their contexts and facilitate the intra-familial dynamics towards valuing pregnancy and birth and ensuring safety of mothers and their babies, both culturally as well as medically.

- Fifth, this study identified that owing to the fear of legal punishment, marriages, births as well as deaths are mostly not registered until the girls (brides) complete the legal age of marriage (20 years). In addition, stillbirths and neonatal deaths are likely to remain unchecked due to an acceptance of such deaths when families and communities do not see any point of registering. Recording and reporting of stillbirths and neonatal deaths are also not taken seriously by the local health system. Such deaths remain invisible in the communities. Relying only on national surveys and extrapolating those rates to the mountainous region is likely to miss the real picture of mountainous districts. Therefore, it would be imperative to plan district specific surveys that can help to identify local mortality rates.

- This study identified a range of policy-practice gaps based on views of frontline health workers and women and families in communities. It would be also imperative to plan critical policy discourse studies including policy documents, and views of policy makers and mid-level managers. Such studies can help to further understand how policy values and strategies could be translated to the implementation settings.

- Finally, from the point of view of frontline health workers, especially female health workers and females SBAs, it would be necessary to investigate addressing their safety and welfare concerns and provide them with secure and comfortable living and working conditions and enable them to serve the local communities well.

9.3 Conclusion

This thesis concludes that in the context of remote mountain villages of Nepal, it is not just about making health services available for women to use during pregnancy, childbirth and the postnatal periods. It is also not just that remoteness is a factor behind the high perinatal mortality rates. Rather, it is critical to address the broader socio-cultural determinants of pregnancy, childbirth and postnatal care to promote perinatal survival in these remote mountainous regions of Nepal.

There is no single solution to address the variety of causes of persisting high perinatal mortality investigated in this study. Policies and programmes have to address religio-cultural aspects of knowledge and behaviour of women and their families, age-old customs of early marriages, and early and repeated pregnancies, perceptions of birth pollution and childbirth in unsafe places (the *Gotha*) and lacunae in the health care system. Localised civil society groups should be entrusted with educating the families to bring about behaviour change and address people's beliefs and practices, while the government should intensively work to close the gaps in its health care system.

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APPENDICES

Appendix 1:   Letter of Introduction and Plain Language Statement

Appendix 2:   Consent Forms and Information Sheets

Appendix 3:   Study Guides (Interview, and Field observation and Document Review)

Appendix 4:   Demographic Profile of Women Interviewed for Research

Appendix 5:   Ethical Approval and Access Letters

Appendix 6:   Glossary of the Key Terms Used (Nepali and English)

Appendix 7:   Initial Coding Framework

Note: Appendix 1, 2 and 3 (3.1) were translated into Nepali language for field use in Nepal

Appendix 1: Letter of Introduction

1.1 Letter of Introduction

Dr. Lareen Newman
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Southgate Institute of Health, Society and Equity, Faculty of Medicine, Nursing and Health Sciences, Flinders University, Adelaide, Australia
GPO Box 2100
Adelaide SA 5001
Tel: +61 8 72218488
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http://www.flinders.edu.au/people/lareen.newman

Flinders UNIVERSITY

LETTER OF INTRODUCTION

Dear (name of informant),

This letter is to introduce Mr Mohan Paudel who is a Doctor of Philosophy candidate in the Southgate Institute for Health, Society and Equity, Faculty of Medicine, Nursing and Health Sciences, Flinders University. He will present his student card, which carries a photograph, as proof of identity.

Mohan is undertaking a research project titled "The Socio-cultural and Healthcare Context of Perinatal and Neonatal Survival in a Rural Mountain District of Nepal". The study explores the experiences of women and their family members, health service providers, health managers and other key informants in the selected mountain districts of Nepal to gain an in-depth understanding of factors including social, cultural and economic factors influencing the survival of newborn babies, the interrelationships between these factors and their policy implications. Mohan's PhD study will lead to the production of a thesis and other publications.

He would like to invite you to assist with this project by participating in an interview session which covers certain aspects of this topic. The interview will take approximately an hour.

Be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions. Non-participation in this study will not affect you in any regards.

The interview will be conducted by Mohan himself who has experience of working in remote areas of Nepal and is familiar with the local culture and language.

Since he intends to make a tape recording of the interview, he will seek your consent, on the attached form, to record the interview, to use the recording or a transcription in preparing the thesis, report or other publications.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on (+61 8 72218488), fax (+61 8 7221 8424) or e-mail (Lareen.newman@flinders.edu.au)

Thank you for your attention and assistance.

Yours sincerely

Dr. Lareen Newman

inspiring achievement

1.2 Plain Language Statement for Consent

The Socio-cultural and Health Care Context of Perinatal Survival in Rural Mountain District of Nepal

Namaste, this is Mohan Paudel. I am from rural village of western part of Nepal. I worked through non-governmental agencies being a trainer/program consultant/program evaluation coordinator for strengthening maternal and newborn health services in remote areas in Nepal. I am currently enrolled in the Degree of Doctor of Philosophy in Flinders University of Australia. This research is being undertaken with the approval of Flinders University. This research is entitled, "The Socio-cultural and Health care Context of Perinatal and Neonatal Survival in a rural Mountain District of Nepal".

I would like to invite you to participate in this research and would be very grateful if you choose to do so. If you agree to participate in this study, you will be asked to share with me your experiences and perceptions about care during and after births and situations that lead to sickness, and deaths of new-born babies. The aim of this research is to explore perspectives of parents, families and health care workers on newborn care and newborn deaths in order to understand what influences newborn survival. The conversation with you will be captured in audio tape through in-depth interviews. The interview lasting approximately an hour will be absolutely confidential. Written transcriptions of these recordings will be made. No names will be attached to the tapes. Code numbers with made up name will be used to identify you in the information provided. Your personal contact details will be kept separately in the event that researcher needs to contact you again during the period of this research.

Prior appointment will be taken for participation in this study. You are free to choose the time and place. If during participation, you wish to continue at another time or discontinue the interview completely, you are free to leave, even if you have agreed at an earlier time. If you feel at any time that you would like to speak to professionals or other persons, you may wish to contact local female community health volunteers or I could assist you to make contact with person that you feel comfortable upon your permission.

Please note that you are free to withdraw this consent at any time during the study for any reason. Your non-participation in this study will not affect you in any regards. If this happens, any information, which has been already collected from you, will be destroyed if you wish. Any questions concerning this study can be directed to Dr. Lareen Newman by telephone Tel: +61872218488, Fax: +61872218424 or e-mail Lareen.newman@flinders.edu.au, Southgate Institute of Health, Society and Equity, Flinders University, Australia.

Appendix 2: Consent Forms and Information Sheets

2.1 Consent Form (Interview Participants)

CONSENT FORM
(Interview participants)

The Socio-cultural and Health care Context of Perinatal Survival in Rural Mountain District of Nepal

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I …...being married and/or over the age of 18 years hereby consent to participate as requested in the 'Letter of Introduction and/or Information Sheet' for the research project on "The Socio-cultural and Health care Context of Perinatal and Neonatal Survival in Rural Mountain Districts of Nepal".

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to audio recording of my information and participation.
4. I understand that:

   - I may not directly benefit from taking part in this research.
   - I am free to withdraw from the project at any time and am free to decline to answer particular questions.
   - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
   - Whether I participate or not, or withdraw after participating, will have no effect to my position.
   - I may ask that the recording/observation be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

Participant's signature………………………………….Date…………………...

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name……………………………….………………………................

Researcher's signature………………………………..Date……………………

2.2 Check List for Verbal Informed Consent (Photograph Release)

The Socio-cultural and Health Care Context of Perinatal Survival in Rural Mountain District
of Nepal

Photo Number:………………………………………………………………..

Nature of research
- Purpose of the research is to explore perspectives on newborn care and neonatal deaths among parents, families and health care workers in order to understand what influences newborn survival.
- Your photo will be useful in presenting the context of care/background analysis in this study

What is being informed to the person?
- The photo could be displayed in academic presentations
- The photo could be displayed in thesis
- The photo could be used in any other future publications related to this study
- The photo will be de-identified by number or pseudonym
- Can refuse to provide photo
- Can request to deleting photo

What will be the use of the Photo?
- This photo will be used to present the rich context of the care and survival
- This photo will add in understanding more about the context of care seeking/receiving, family and health care practices related to essential neonatal care.
- This photo will not affect your personal, family and social life
- It is not related to any public and private organizations
- This photo will be used in presentations, thesis and future publications related to my PhD degree

Confidentiality
- I will store your photo in my computer/hard drive
- It will not have your name on it
- I will use a substitute name to use in research, you can advise if you have any preferred name to use
- Any time I refer to your photo, I will use the made up name
- Neither researcher nor other people involved study will discuss this photo with your name in relation to this research

Contact details
- My phone number is 9841398023 (Local Number).
- I am living at your community (inform the house living at the time of fieldwork)
- My email is paud0005@flinders.edu.au, you can ask people to write mail to me
- If you want to contact me after I left Nepal, you can contact me on +61 424847744
- If you want to contact my supervisor at the university, her name is Dr. Lareen Newman, email address lareen.newman@flinders.edu.au

2.3 Information Sheet

INFORMATION SHEET

(Interviews – Woman & Her Family Members)

Title: 'The Socio-cultural and Health Care Context of Perinatal Survival in Rural Mountain District of Nepal'

Thank you for showing an interest in this project. Please, read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

Description of the study:

This project is being undertaken as part of the requirement for Mr. Mohan Paudel's Doctor of Philosophy (PhD) titled 'The Socio-cultural and Health care Context of Perinatal and Neonatal Survival in Rural Mountain Districts of Nepal' which is supported by Flinders University. The project will investigate the factors influencing perinatal and neonatal survival in rural mountain districts of Nepal.

Purpose of the study:

This project aims to explore factors influencing perinatal and newborn survival in a rural mountain district of Nepal. The project seeks to unravel the socio-cultural and health care context by understanding the experiences of affected families (families of deceased newborns, perinatal deaths, sick and/or small sized newborns), health service providers, health volunteers, health managers and key stakeholders working in/for maternal and neonatal health care of rural mountain region of Nepal.

What will I be asked to do?

You are invited to attend a one-on-one interview with the researcher (Mr. Mohan Paudel) who will ask you some questions about your perceptions and experiences surrounding the care of newborn babies when they are born and soon afterwards, your experiences and/or opinions on seeking and receiving or providing care for mothers and new babies, and your experiences related to situations that lead to the deaths of babies during pregnancy and within the first month of life. The interview will take approximately 30 to 40 minutes and will be scheduled at your preferred time and venue. The interview will be recorded using a tape recorder to help the researcher with looking at the results. Once recorded, the interview will be typed-up and stored as a computer file and then destroyed once the results have been finalised.

What benefit will I gain from being involved in this study?

Sharing your experiences will help to better understand the local context and reality of perinatal and newborn care and the way babies are cared for. This will eventually help to prevent occurrence of deaths of babies before they are born and soon afterwards in other families by improving the planning and delivery of future programs for health care and survival of babies in your community and other similar communities of Nepal's rural mountainous region. It could inspire local, national and international communities in emphasizing the design and implementation of program fitting to local socio-cultural and health care context.

Will I be identifiable by being involved in this study?

We will treat any information provided by you as an individual in the strictest confidence and you will not be individually identifiable. Interview will be taken in the place which you find safe, convenient and confidential. During your interview if you wish to involve any senior members of your family, such as husband or mother-in-law, that will be accepted. However, researcher will be very pleased to organize a separate interview with other family members in order to better concentrate on their experience.

To ensure your confidentiality we will maintain a central database of participants that is only available to the researcher (Mohan) and his supervisors. You may choose a name (pseudonym) for yourself which will be used in any published work related to this study. The information available to my supervisors will use the pseudonyms rather than the names of informants. The recording and transcript of your interview will be labelled with this pseudonym to protect your identity.

Are there any risks or discomforts if I am involved?

Given that we are discussing issues regarding the deaths before birth, and sickness and deaths of newborn babies, there is potential that this process might make you feel discomfort. During the process of interview, you might remember other people or your own experience surrounding the deaths of a baby or babies, which might be an uncomfortable emotional experience. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the investigator. You can stop sharing your experience at any time, can reschedule to talk another time, or can just cancel the interview.

How do I agree to participate?

Participation is voluntary. You may answer 'no comment', 'I don't know' or you can refuse to answer any questions and you are free to withdraw from the interview at any time without effect or consequences. Your denial to participate in interview will not affect you in any regards. If you wish to ask permission from any of your senior family members—husband or mother-in-law, that will be as per your choice.

A letter of introduction accompanies this information sheet. If you agree to participate please read (or the researcher-Mohan Paudel can read loud for you to listen) and ask your verbal consent to participate in the study.

How will I receive feedback?

The summary of what the project finds will be published through local news media in Nepali language and be provided to the local Regional and District Health Offices. The detailed study report (thesis) will be available at Flinders University's dissertation repository.

How can I find out more information?

If you have any concern and queries regarding your involvement in this project, you are encouraged to contact **Mohan Paudel** by telephone: +9779841398023 (while in Nepal); +61 424847744 (while in Australia) or by email paud0005@flinders.edu.au.

Any enquiries you may have concerning this project should be directed to Dr Lareen Newman by telephone 0061872218488, fax 0061872218424 or e-mail Lareen.Newman@flinders.edu.au.

Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.

INFORMATION SHEET

(Interview – Health Service Provider and Other Key Informants)

Title: 'The Socio-cultural and Health Care Context of Perinatal Survival in Rural Mountain District of Nepal'

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

Description of the study:

This project is being undertaken as part of the requirement for Mr. Mohan Paudel's Doctor of Philosophy (PhD) titled 'The Socio-cultural and Health care Context of Perinatal and Neonatal Survival in Rural Mountain Districts of Nepal' which is supported by Flinders University. The project will investigate the factors influencing perinatal and neonatal survival in rural mountain districts of Nepal.

Purpose of the study:

This project aims to explore factors influencing perinatal and newborn survival in a rural mountain district of Nepal. The project seeks to unravel the socio-cultural and health care context by understanding the experiences of affected families (families of deceased newborns, perinatal deaths, sick and/or small sized newborns), health service providers, health volunteers, health managers and key stakeholders working in/for maternal and neonatal health care of rural mountain region of Nepal.

What will I be asked to do?

You are invited to attend a one-on-one interview with the researcher (Mr. Mohan Paudel) who will ask you some questions about your perceptions and experiences surrounding the health of newborn babies when they are born and soon afterwards, your experiences and/or opinions on providing care for mothers and new babies, and your experiences related to situations that lead to the deaths of babies during pregnancy and within the first month of life: socio-cultural aspects in the communities such as values, beliefs you have observed and any aspects related to maternity and neonatal health care provision from facility-based institutions, outreach and community platforms and home visits. The interview will take approximately 30 to 40 minutes and will be scheduled at your preferred time and venue. The interview will be recorded using a tape recorder to help the researcher with looking at the results. Once recorded, the interview will be typed-up and stored as a computer file and then destroyed once the results have been finalised.

What benefit will I gain from being involved in this study?

The sharing of your experiences will help to better understand the local context and reality of health and the way newborn babies are cared for. This will eventually help to improve the planning and delivery of future

programs for health and survival of babies during pregnancy and after birth in first month of their life in Nepal's rural mountainous region.

Will I be identifiable by being involved in this study?

We will treat any information provided by you as an individual in the strictest confidence and you will not be individually identifiable.

To ensure your confidentiality we will maintain a central database of participants that is only available to the researcher (Mohan Paudel) and his supervisors. You may choose a name (pseudonym) for yourself which will be used in any published work related to this study. The information available to my supervisors will use the pseudonyms rather the names of informants. The recording and transcript of your interview will be labelled with this pseudonym to protect your identity.

Are there any risks or discomforts if I am involved?

Given that we are discussing issues regarding the deaths before birth, and sickness and deaths of newborn babies, there is potential that this process might make you feel discomfort. During the process of interview, you might remember the bitter moment of baby dying; treating/referring a sickly and/or low birth weight baby, mother delivering a dead baby or you and the family getting in difficult situation of the baby suffering in a situation of life and death; which might be an uncomfortable emotional experience. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the investigator. You can stop sharing your experience at any time, can reschedule to talk another time, or can just cancel the interview.

How do I agree to participate?

Participation is voluntary. You may answer 'no comment', 'I don't know' or you can refuse to answer any questions and you are free to withdraw from the interview at any time without effect or consequences. Your denial to participate in interview will not affect your position and your work as a health service provider in any regards.

A letter of introduction accompanies this information sheet. If you agree to participate please read and respond your consent for whether to participate in the study.

How will I receive feedback?

The summary of what the project finds will be published through local news media in Nepali language and be provided to the local Regional and District Health Offices. The detailed study report (thesis) will be available at Flinders University's dissertation repository.

How can I find out more information?

If you have any concern and queries regarding your involvement in this project, you are encouraged to contact **Mohan Paudel** by telephone: +9779841398023 (while in Nepal); +61 424847744 (while in Australia) or by email paud0005@flinders.edu.au.

Any enquiries you may have concerning this project should be directed to Dr Lareen Newman by telephone 0061872218488, fax 0061872218424 or e-mail Lareen.Newman@flinders.edu.au.

Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 6702). For more information regarding ethical approval of the project the Executive Officer of the

Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix 3: Study Guides (Interview, and Field observation and Document Review)

3.1 IN-DEPTH INTERVIEW GUIDE

(Approximate time duration 30 to 40 minutes)

THE SOCIO-CULTURAL AND HEALTH CARE CONTEXT OF PERINATAL SURVIVAL IN RURAL MOUNTAIN
DISTRICT OF NEPAL

_____

A.   Women's Interview

Socio-demographic profile

1.   Just to start our discussion, perhaps you can tell me about yourself- you and your family?

>   (Probe: completed age (years), marital age, current marital status, family size, caste/ethnicity, participant's education, husband's education, personal habits (drinking, smoking) and so on.)

2.   Can you tell me how you and your family manage to live here?

>   (Probe: living and working conditions, occupation of participant, her husband and other key family members, household wealth (major income source, land availability, food sufficiency, means of transport, housing type, toilet facility, kitchen-indoor air etc.] ; Interviewer Notes: needs general observation also…)

Maternal characteristics

3.   Can you briefly describe to me your childbearing history?

>   (Probe: age at first birth, gravida/parity including losses, current pregnancy, previous spacing, intended/unintended births including any incidents of family violence, family planning)

Perceptions about care seeking and survival

4.   What do you think (believe) about seeking health care during pregnancy, during labour/birth, immediately after the birth for mother/baby, during the early weeks? Are there any special situations? Why? Why not?)

5.   Have you heard of any things that the mother, family or health worker or anyone else can do to make it more likely that the baby is born healthy and survives?

>   (Probe: beliefs, knowledge, health system, acceptance of the formal care: Antenatal visits, TT immunization, Iron intake, Birth preparedness (have money, transportation, known to Skilled Birth Attendant and health facility, postnatal care – clean cord cutting, breastfeeding, immediate drying/warmth etc.)

6.   Can you tell me about things that you or others do to care for the baby as soon as it is born, within the first month?

>   (Probe: health behaviours, acceptance of the formal care: Immediate neonatal care practices (drying/wrapping, keeping warm/cool, breastfeeding, cord-care, delay bathing); new-born care visits, pre-lacteal feedings)

When do you think the baby is sick or baby is in difficult condition? What do you think can be done when the baby is sick? Where to take it for help? Why? Why not?

Experience of care

7. Can you describe to me your experience of the care you received during your last pregnancy, the last birth and after the birth up until the first month?

   (Probe: care at home, care at health facility, birth preparedness-knows and decides where to deliver, money, transportation, and support from family] Note: focus also on other than the last pregnancy if it is interesting and relevant to the phenomenon-i.e. loss, sickness &/or small sized baby

Experience of sickness/stillbirth/neonatal death

8. Can you share me about your most recent story of losing a baby (or having a new baby who is small or sick)?

   What was it? When did it happen?

   Did you go anywhere to prevent/treat it? Do you have any ideas about why it happened?

   Do others think or say anything about why they think it happened? (For example by husband? mother-in-law? health workers?)

   (Probe: the event (perinatal death, neonatal death, sick/small sized new-born), Interviewer Note: this is the central aim, take time in in-depth probing of the story)

9. (Only for mothers whose babies are/were sick). Would you describe how you cared (or caring now) for your baby while it is/was sick?

   What was the care specifically-what, where & when? Care at home? Contacted other traditional healers? Facility based care? Contacted female community health volunteers, health facility and hospital? Private nursing home?)

   If no facility-based care, why?

   (Probe: Response to the event)

10. Do you think this particular event (referred to either 8 &/or9) could have been prevented in anyway?

    How? *(ask with an intention to help other women, assure not to make the woman feeling guilty about her lose)*

    (Probe: role of husbands, mother in laws, other family members, female community health volunteers and health workers, Expectations from family (husband, mother in law) and facility-based institutional care)

11. In relation to the event (8 &/ or 9) did you have any chance to consult a health facility or to have home visits from health workers/volunteers/health workers? How did you experience it?

    (Probe: the care from female community health volunteers, health workers-doctor, nurse, referral and compliance-if not why? Care from traditional healers? Quality of care, compliance, referral, constraints/enablers in access to care)

    Do you think the care you received (or didn't receive) contributed in any way to this event happening or to preventing it being worse? How?

12. Can you tell me about any other problems that you experienced during pregnancy? Childbirth? When you were pregnant with the baby (related to the event above—Sickness, Stillbirth or Neonatal Death)

    (Probe: health problems, experience of delays-seeking/receiving care, Note: focus also on other pregnancies and if similar previous events had occurred in the woman's life provided it is interesting and relevant to the phenomenon-i.e. loss, sickness &/or small sized baby)

13. Did you find any other women having the similar problem (Sickness/Stillbirth/Neonatal Death) in your community?

(Probe: Other similar events in the community and opinion on prevention)

Why do you think that they had to experience such events?

Do you have any ideas about what might help prevent this situation happening again for yourself or your neighbours?

14. Do you have any other comments you would like to add, or any questions you would like to ask?

B. Family Members (husbands, mothers-in-law, fathers-in-law)

(Additional questions to Section A, as relevant)

1. Can you tell me about any other problems that you as a family member experienced about her (the woman's) pregnancy? Childbirth? When she was (the woman) pregnant with the baby (sick, stillbirth, newborn death)

2. Do you have any different observations/views about the loss of baby? Health care seeking? Anything else?

C. Female Community Health Volunteers

1. What do you think the ways you can contribute as a volunteer to make it more likely that the baby is born healthy and survives?

(Probe: her perceived roles)

2. Can you share with me the family's [referred to the particular woman] most recent story of losing a baby (or having a new baby who is small or sick)?

What was it? When did it happen?

Did they go anywhere to prevent/treat it? Do you have any ideas about why that happened? Could you help this family? How?

(Probe: the event (perinatal death, neonatal death, sick/small sized new-born), Interviewer Note: this is the central aim, take time in in-depth probing of the story)

3. (Only if the family had sick & or small sized baby). Would you describe how you supported to care (or caring now) for the baby while it is/was sick/small sized?

What was the care specifically-what, where & when? Care at home? Contacted other traditional healers? Facility based care?)

If no facility-based institutional care, why?

(Probe: Response to the event)

4. Do you think this particular event (referred to either 2 &/or 3) could have been prevented in anyway?

How? (ensure that there is no blame to each-others, rather let her fully explain the story)

What did the family could do to prevent it? Was that enough? Why not? Why do you think that they could not do it?

(Probe: your role and family's expectation of facility-based institutional care, barriers and enablers, health volunteer's perception of traditional and institutional care)

5. Can you tell me about any other problems that you as a female community health volunteer experienced about her (the woman's) pregnancy? Childbirth? When she was (the woman) pregnant with the baby (related to the event above)

   (Probe: experience of delays-seeking/receiving care, Note: focus also on other pregnancies and if similar previous events had occurred in the woman's life provided it is interesting and relevant to the phenomenon-i.e. loss, sickness &/or small sized baby)

6. Did you find any other women having the similar problem (the events) in your community?

   (Probe: Other similar events in the community and opinion on prevention)

   Why do you think that they had to experience such events?

   Do you have any ideas about what might help prevent this situation happening again for yourself or your neighbours?

7. Do you have any other comments you would like to add, or any questions you would like to ask?

D. Health Service Providers and Other Key Informants

1. Can you describe your experience of working as a health worker with pregnant women and new mothers?

   [Probe: years of experience, specific trainings received in maternity and newborn care, work duration in particular village/health facility]

2. Can you describe what sorts of services this health facility provides?

   [Probe: provide to moms and new-born? range of care and services delivered from the facility]

3. In what different ways are you contributing in providing essential care to new-borns from this health facility?

   [Probe: perceived roles, skills, knowledge: immediate care of babies after birth, care for low birth weight babies, care during sickness: managing infections-diarrhoea, pneumonia, resuscitation……..]

4. Data shows the situation of survival of newborn babies in the mountain region is worst in the country. Mugu is also considered as a mountain district with poor child/newborn survival, what do you think the reasons behind?

   (Probe: care seeking for women-babies, quality of care from health facilities)

5. Do you think any aspects of the health care system contribute to these events despite people's efforts?

   [Probe: health care skills, training, resources supports available to health facility, referral and related problems, incentives/motivation to work, supports from supervisory institution; Why? Why not?]

6. Do you think these events could be prevented in anyway?

7. Are women in this district/community seeking care during their pregnancy/birth/postnatal period for themselves and their babies? How is this trend from health facility? If not so encouraging, why? (Probe: the perspectives of health worker on enablers, constraints, care at home, traditional care, facility-based institutional care)

8. Can you share with me the last event [referred to the particular one from the woman's interview or any other event] ---most recent story of losing a baby (or having a new baby who is small or sick)? What was it? When did it happen?

   Did they go anywhere to prevent/treat it? Do you have any ideas about why that happened? How did you help this family?

   (Probe: the event (perinatal death, neonatal death, sick/small sized new-born), Interviewer Note: this is the central aim, take time in in-depth probing of the story)

9. Do you think this particular event could have been prevented in anyway? How?

   What did the family could do to prevent it? Was that enough? Why not?

   What was the role of your health facility?

   [Probe: your expectations from the family? observed any delays/constraints at home, community level, facilitation of the case at health facility] The policy/strategy vs local health context; socio-cultural context

   Do you have any ideas about what might help prevent this situation happening again for the woman/family or anyone in this community?

10. Do you have any other comments you would like to add, or any questions you would like to ask?

                                                                                    ###

THANK YOU SO MUCH FOR YOUR TIME AND SUPPORT.

3.2 OTHER GUIDES (GENERAL OBSERVATION AND DOCUMENT REVIEW)

3.2.1 Guide for general observation

SN	What to observe	Purpose (key points to note)
1	Training of health workers, health volunteers Review workshops, meetings (facility committee, health staff, female community health volunteers) Meeting agendas/minutes of District Health Office/peripheral health facilities	To be able to better understand the context, problems raised, actions planned; and to be able to compare the information provided in trainings
2	Recording/Reporting/Dissemination of information in health facility	To provide behaviour change strategies, the mortality pattern
3	Health Facility (birthing room, infra-structure, postnatal room	To provide general description in the thesis, against which to provide parents/community views of facilities
4	The geography, road, study site, women in working in the field, coming to health facilities	To provide general description of study site in the thesis
5	Work of any relevant International/Non-Governmental Organizations	To provide background information to augment the description of the health care available in the district/villages
6	Family/household-living condition, birthing sites, newborn clothes….	To provide general description of study site in the thesis

3.3.2 Document Review Sheet - Neonatal Interventions and Care provision

The main intention of the review is to examine any priority for rural and mountainous region, the ways/approaches to improve perinatal and neonatal survival, the type and nature of interventions proposed and any implementation directions. This will allow comparison with local approaches to identify any policy-practice gaps in what is provided and what is needed. This will also help to ask appropriate questions to the health managers & other key informants referring to the existing policy/strategies and will provide a broader health care context to introduce the introductory chapter of the thesis.

	Name of the National Document	Year of Issue	Effective duration	Major Points covered in the documents			Focus for Rural and Mountainous Region	Comments
				Home	Community	Health Facility		
1	Nepal National Neonatal Health Strategy	2004	2004 to Current					
2	Safe motherhood and Neonatal Health Long-term Plan	2005	2005-2017					
3	Skilled Birth Attendant Policy	2006	2006 to Current					
4	Program Management Guideline (Community Based Integrated Management Of Childhood Illness)							
5	Program Management Guideline (Community Based Newborn Care)							
6	Program Management Guideline (Maternal and Newborn Health)							

Appendix 4: Demographic Profile of Women Interviewed for Research

SN	Interview Participant [Name]	Age	Religion/Ethnicity	Caste Level [upper, lower]	Education Woman [illiterate, grade]	Education husband	Source of Income	Age at Marriage	Number of Pregnancy	Number of losses	Nature of Loss [Abortion (A), Stillbirth (SB), Neonatal (NND), Infant (ID), Under-five deaths (U5D)]	Interview site	Family members who added in the interview
1	*Deviram	18	Hindu/*Khas*	Upper	Illiterate	*literate*	*Labour*	15	2	0	NA	*Home*	*Mother, Uncle*
2	Devkumari	27	Hindu/*Khas*	Upper	Illiterate	12	Service	19	5	2	NND: 2, on 10th day	Home	Husband, Mother-in-law
3	Devika (Devilal)	20	Hindu/*Khas*	Upper	10	11	Farmer	17	2	1	NND: 1 on 3rd day	Home	Husband
4	Birupa (Biniram)	19	Hindu/*Khas*	Upper	11	11	Farmer	16	3	2	NND: 1, SB: 1	Home	Husband, Father-in-law
5	Hashamati	25	Hindu/*Khas*	Upper	Illiterate	12	Labour	17	5	2	SB: 1, A: 1	Home	
6	Junamati	25	Hindu/*Khas*	Lower	Illiterate	Illiterate	Labour	11	4	1	SB:1	On the Way plus home	Sister-in-law, Father
7	Sita	20	Hindu/*Khas*	Lower	Illiterate	Illiterate	Labour	18	3	2	NND: 1 on 30th day A:1	On the Way plus home	
8	Sunita	20	Hindu/*Khas*	Upper	11	Bachelor	Farmer	17	1	1	NND: 1 on 3rd day	Home	Mother-in-law
9	Yesoda	25	Hindu/*Khas*	Upper	12	12	Farmer	16	4	3	NND:1 on 3rd day, SB:1, A:1	Home	
10	Laldevi	17	Hindu/*Khas*	Upper	9	10	Farmer	16	1	1	ID: 1 on 33rd day	Home	Mother-in-law

11	Ramkali	18	Hindu/*Khas*	Upper	Illiterate	12	Farmer	14	2	1	NND: 1 on the day of birth	Home	Father-in-law
12	Aspura	26	Hindu/*Khas*	Upper	Literate	10	Farmer	15	5	2	NND: 2 on 7th and 8th day of births	Home	
13	Balaram/Binita	20	Hindu/*Khas*	Upper	Literate	2	Labour	14	4	2	SB: 1, ID:1	Home	Husband
14	Punchamaya	35	Hindu/*Khas*	Lower	Illiterate	Illiterate	Labour	15	10	3	NND: 1 on the day of birth, ID: 1, U5D: 1	Home	Husband
15	Rupamati	20	Hindu/*Khas*	Lower	Illiterate	5	Labour	12	3	1	NND:1, 20th day of birth	Punchamaya's home	Husband
16	Jasikala	19	Hindu/*Khas*	Upper	Illiterate	9	Farmer	16	2	2	NND: 2, on the day of birth	Home+ tea shop	Husband
17	Kushumkali	31	Hindu/*Khas*	Lower	Illiterate	5	Labour	14	9	5	NND: 2 on the 5th and 7th day of birth, U5D: 1, A: 2	Home	Husband
18	Fuladevi	18	Hindu/*Khas*	Lower	9	5	Farmer	14	2	1	NND: 1 on the 15th day of birth	Home	Husband
19	Hashakali	25	Hindu/*Khas*	Lower	Illiterate	9	Labour	15	9	5	A+SB: 2, A: 3	Home	
20	Sumitra	19	Hindu/*Khas*	Upper	10	12	Farmer	16	2	1	NND: 1 on the 9th day of birth	Home	Mother-in-law, Grand Mother-in-law
21	Latima	32	Hindu/*Khas*	Upper	Illiterate	Illiterate	Labour	14	10	7	NND: 1 on the 6th day of birth, SB: 2, ID: 3, U5D:1	Home	Husband
22	Bishnumaya	20	Hindu/*Khas*	Upper	4	10	Farmer	15	4	3	NND: 2 on the first day of birth, SB: 1	Home	Father-in-law
23	Dhansila	39	Hindu/*Khas*	Lower	Illiterate	Illiterate	Farmer	18	5	1	SB: 1	Home	

24	Beldevi	27	Hindu/*Khas*	Lower	Illiterate	3	Labour	14	4	1	SB: 1	On the way	Husband
25	Shivakumari	18	Hindu/*Khas*	Upper	8	9	Farmer	15	1	1	NND: 1 on the 7th day of birth	Home	Mother-in-law
26	Kunjong	22	Buddhism/*Lama*	Upper	Illiterate	9	Farmer	20	1	1	NND: 1 on the day of birth	Home	Husband
27	Gobnajong	34	Buddhism/*Lama*	Upper	Illiterate	Illiterate	Farmer	20	5	2	SB: 2	Home	Husband
28	*Karma*jong	22	Buddhism/*Lama*	Upper	Illiterate	Illiterate	Farmer	18	2	1	NND: 1 on the 1st day of birth	Home	Mother-in-law
29	Tenghmu	22	Buddhism/*Lama*	Upper	Illiterate	Bachelor	Employment	15	3	1	NND: 1 on the 2nd day of birth	Home	
30	Penghmu	16	Buddhism/*Lama*	Lower	Illiterate	Illiterate	Farmer	14	1	1	NND: 1 on the first day of birth	Home	
31	Yanghmu	28	Buddhism/*Lama*	Upper	Illiterate	Illiterate	Farmer		2	2	SB: 2	Home	
32	Chhitorje	21	Buddhism/*Lama*	Upper	Illiterate	11	Carpentry	16	3	#REF!	SB: 1	Home	
33	Dorjing (Dolma)	25	Buddhism/*Lama*	Upper	Illiterate	literate	Farmer	22	2	1	NND: 1 on the day of birth	Home	Husband
34	Kanghmu	25	Buddhism/*Lama*	Upper	Illiterate	Illiterate	Farmer	16	4	2	NND: 1 on the 11th day of birth, ID: 1	Home	
35	Hitchma	24	Buddhism/*Lama*	Upper	Illiterate	11	Farmer	19	2	1	NND: 1 on the 15th day of birth	Home	
36	Yanghmo	25	Buddhism/*Lama*	Upper	Illiterate	literate	Farmer	18	2	1	SB: 1	Home	
37	Tengri	18	Buddhism/*Lama*	Upper	Illiterate	Illiterate	Farmer	17	1	1	NND: 1 on the 27th day of birth	Home	Mother-in-law, Father-in-law

38	Saradevi	18	Hindu/*Khas*	Upper	2	6	Farmer	13	2	1	NND: 1 on the day of birth	Home	
39	Jayadevi	22	Hindu/*Khas*	Lower	Illiterate	Illiterate	Farmer	16	3	2	SB+NND: 1 on the 3rd day of birth, SB: 1	Home	Mother-in-law
40	Bishnumati	31	Hindu/*Khas*	Lower	Illiterate	Illiterate	Labour	17	6	2	NND: 1 on the 15th day of birth, SB: 1	Home	Husband
41	Batuli	31	Hindu/*Khas*	Upper	Literate	literate	Farmer	15	8	3	ID: 1, U5D: 1, A:1	Home	Father-in-law
42	*Dilma's [Mother-in-law]*	21	Hindu/*Khas*	Upper	Illiterate	literate	*Farmer*	18	2	2	NND: 2 on the 10th and 15th day of birth	*Home*	

Notes

Total losses (Abortion + Stillbirths+ Infant +Under-five deaths): 75

Newborn Deaths: 35

Stillbirths: 20

Infant/under-five deaths: 9

Deaths within last 4 years: 33 newborn deaths, 23 early neonatal deaths, 16 stillbirths

- * Only participant 1 is male, he lost his wife on 18th day at birth, has a newborn and a toddler in the care of his mother, the demographic features describe his wife. He is 25, illiterate and a labourer.

- Participants: 7, 13, 14, 15, 18, 19, 22, 33, 34, 41 were pregnant at the time of interview.

- Participant 42, though Dilma agreed to be interviewed, I could contact only her mother-in-law for the interview. She is 61, illiterate with 2 daughters-in-law and 2 sons. The demographic features in the table describe her daughter-in-law who lost 2 newborns.

- All participants have gone through current perinatal losses in the last 4 years except participant 1 (maternal death, baby survives), 42 (she is a MIL with perinatal loss of daughter-in-law), Bishnumati (postnatal, a perinatal loss 4 years ago), Punchamaya (current pregnant, and a traditional birth attendant with a perinatal loss 4 years ago), Batuli (current pregnant, with abortions, and infant and under-5 deaths).

- Women have been dominant in all the interviews except in 3, 4, 13, and 21 where husbands talked more, and wives added their comments.

- The names of the participants are pseudo names.

Appendix 5: Ethical Approval and Access Letters

5.1: Social and Behavioural Research Ethics Committee, Flinders University

Dear Mohan,

The Chair of the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University considered your response to conditional approval out of session and your project has now been granted final ethics approval. This means that you now have approval to commence your research. Your ethics final approval notice can be found below.

FINAL APPROVAL NOTICE

Project No.:	**6702**
Project Title:	The Socio-cultural and Healthcare Context of Perinatal and Neonatal Survival in a Rural Mountain District of Nepal
Principal Researcher:	Mr Mohan Paudel
Email:	paud0005@flinders.edu.au

Approval Date:	27 November 2014	Ethics Approval Expiry Date:	**3 March 2019**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided with the addition of the following comment(s):

Additional information required following commencement of research:

1. Please ensure that copies of the correspondence granting permission to conduct the research from the Nepal Health Research Council (NHRC) are submitted to the Committee *on receipt.* Please ensure that the SBREC project number is included in the subject line of any permission emails forwarded to the Committee. Please note that data collection should not commence until the researcher has received the relevant permissions (item D8)

    Provision of a copy of the ethics approval notice from the Ethical Review Board of Nepal Health Research Council *on receipt.* Please note that data collection should not commence until the researcher has received the relevant ethics committee approvals (item G1)

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. **Participant Documentation**
    Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

    •all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.

    •the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be

used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.

- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

2.   **Annual Progress / Final Reports**
In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress report must be submitted each year on the **27 November** (approval anniversary date) for the duration of the ethics approval using the annual / final report pro forma available from Annual / Final Reports SBREC web page.*Please retain this notice for reference when completing annual progress or final reports.*

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request <u>and</u> an annual report.

<u>Student Projects</u>
The SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, reviewed and approved. This is to protect the student in the event that reviewers recommend some changes that may include the collection of additional participant data.

Your first report is due on **27 November 2015** or on completion of the project, whichever is the earliest.

3.   **Modifications to Project**
Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such matters include:

- proposed changes to the research protocol;
- proposed changes to participant recruitment methods;
- amendments to participant documentation and/or research tools;
- change of project title;
- extension of ethics approval expiry date; and
- changes to the research team (addition, removals, supervisor changes).

To notify the Committee of any proposed modifications to the project please submit a Modification Request Form to the Executive Officer. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted <u>prior</u> to the Ethics Approval Expiry Date listed on this notice.

<u>Change of Contact Details</u>
Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

4.   **Adverse Events and/or Complaints**
Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforseen event occurs that may affect the ethical acceptability of the project.

Kind regards
  Rae

Mrs Andrea Fiegert and Ms Rae Tyler
Ethics Officers and Executive Officer, Social and Behavioural Research Ethics Committee
Andrea - Telephone: +61 8 8201-3116 | Monday, Tuesday, Wednesday and Thursday morning
Rae – Telephone: +61 8 8201-7938 | ½ day Wednesday, Thursday and Friday

Email: human.researchethics@flinders.edu.au
Web: Social and Behavioural Research Ethics Committee (SBREC)

Manager, Research Ethics and Integrity – Dr Peter Wigley
Telephone: +61 8 8201-5466 | email: peter.wigley@flinders.edu.au

Research Services Office | Union Building Basement
Flinders University
Sturt Road, Bedford Park | South Australia | 5042
GPO Box 2100 | Adelaide SA 5001

5.2: Nepal Health Research Council

Nepal Health Research Council
Estd. 1991

Ref. No.: 901

22 December 2014

Mr. Mohan Paudel
Principal Investigator
Southgate Institute for Health, Society & Equity: School of Medicine
Flinders University, Australia

Ref: Approval of Research Proposal entitled **The Socio-cultural and Healthcare Context of Perinatal and Neonatal Survival in a Rural Mountain District of Nepal**

Dear Mr. Paudel,

It is my pleasure to inform you that the above-mentioned proposal submitted on 01 December 2014 (**Reg. no. 271/2014** please use this Reg. No. during further correspondence) has been approved by NHRC Ethical Review Board on 19 December 2014 (2071- 9-4).

As per NHRC rules and regulations, the investigator has to strictly follow the protocol stipulated in the proposal. Any change in objective(s), problem statement, research question or hypothesis, methodology, implementation procedure, data management and budget that may be necessary in course of the implementation of the research proposal can only be made so and implemented after prior approval from this council. Thus, it is compulsory to submit the detail of such changes intended or desired with justification prior to actual change in the protocol.

If the researcher requires transfer of the bio samples to other countries, the investigator should apply to the NHRC for the permission.

Further, the researchers are directed to strictly abide by the National Ethical Guidelines published by NHRC during the implementation of their research proposal and submit progress report and full or summary report upon completion.

As per your research proposal, the total research amount is **NRs. 63,200.00** and accordingly the processing fee amounts to **NRs- 10,158.00.** It is acknowledged that the above-mentioned processing fee has been received at NHRC.

If you have any questions, please contact the Ethical Review M & E section of NHRC.

Thanking you.

Dr. Khem Bahadur Karki
Member-Secretary

5.3: Study District, District Health Office, Mugu, Nepal

Government Of Nepal

Ministry of Health & Population
Department of Health services
Mid -west Regional Directorate

District Health Office

Mugu

Ref: 257

Date : 21 Sep 2014

To,
The Chair Person
The Social and Behavioural Research Ethics Committee,
Flinders University, Adelaide, Australia.

Subject: Supporting Letter for Mr Mohan Paudel's PhD Research Work in Mugu, Nepal

Dear Sir/Madam,
I refer to correspondence between myself and Mr. Mohan Paudel about his interest to
conduct fieldwork for his PhD research project entitled "The Socio-cultural and Health
Care Context of Perinatal and Neonatal Survival in a Mountain District of Nepal". It
would be my pleasure to support Mr. Paudel in relation to his fieldwork in our Mugu
District. As the Chief of the District Health Office, I would be pleased to provide access
for Mr. Paudel to review the data which we routinely collect related to infant, perinatal
and neonatal deaths and permitting him to carry out observations of our health facilities
and conduct other required field work for the purpose of this research in Mugu District.
The District Health Office of Mugu will also be happy to cooperate with him to provide
supports during his field work to conduct his research work in the district, including
access to health professionals and health worker volunteers. Thank you!

Kind Regards

Roshan Lal Chaudhary
District Health Officer

निमित जिल्ला स्वास्थ्य प्रमुख

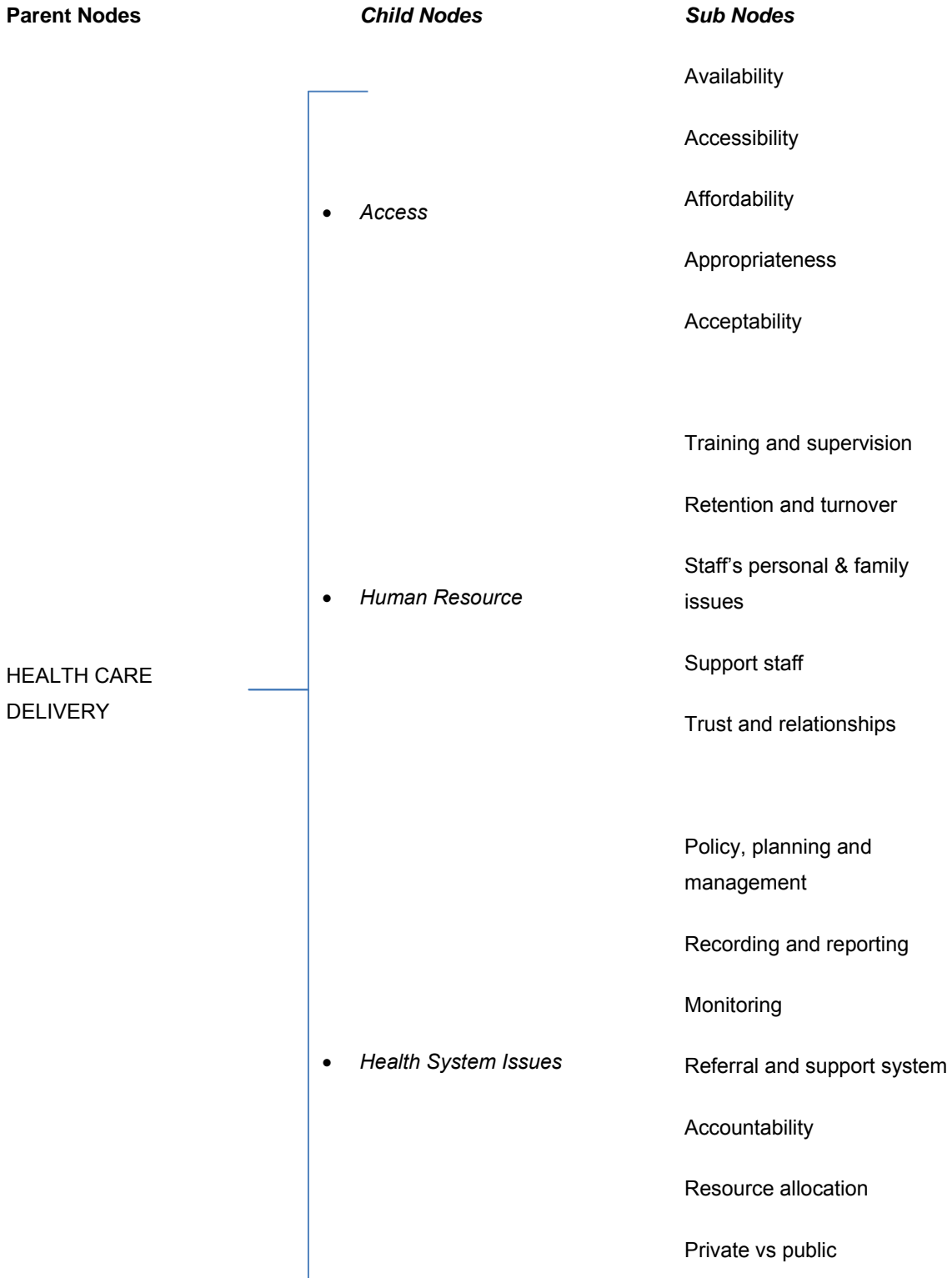## Appendix 6. Glossary of the Key Terms Used (Nepali and English)

Terms in Nepali	Equivalent/nearest terms or meanings in English
Aadanjhadne	Premature births
Aangjhadne	Uterine prolapse
Ala	Stethoscope
Ban Dewata	Forest God
Banlagne/Chhitopadne	Sudden attack
Bhagya	Fate, interchangeably used with *Karma*
Bhaikana mareko	Died after livebirth
Bhote, Bhotebhasa	A descendent of *Bhote or Tibetan*; *Bhotebhas* refers to the language of *Bhote* (Tibet) which the *Lama* people use in their day to day conversations.
Boksi/Bokso/Koptini	Influence of evil eyes
Chhaith	The 6th day celebration after birth wishing a good luck to the baby
Chhuhi	Pollution
Dewata	God, Goddess
Dewatalagne	Influence of God
Dhami, Dhamilo, Dhami Vidhya	A faith healer in *Khas* community is called *Dhami*. The act of practising this faith healing is called *Dhamilo*, and the knowledge, skill and attributes to become a *Dhami* is called *Dhamividhya*.
Dhamilo Kaajkriya	The Hindu's 13 day mourning after death of parents, which is observed as a ritual wishing for the deceased person's afterlife peace and prosperity in heaven.
Garud	Name of a bird which is believed as a carrier of lord Vishnu
Gharbar/Gharbarbasne	Settlement, referred mainly to a girl's marital settlement in in-laws' family
Gotha	Cowshed, refers to the space on the Ground floor of the house that is shared with cattle.
Gothmai Mareko	Died during confinement in *Gotha*
Grahalagne	Influence of astrological hindrance
Gyana	The act of worshipping to please God, inviting *Lama* to pray God
Hadne/Hadnebhayera	When a baby has just begun to walk a few steps
Hudaimareko	Stillbirth

Hunemahina	The last month of pregnancy
Kanyadan	Marriage, considered mainly to be a religious act of offering one's daughter (bride) to bride groom.
Karma	Past deeds of in previous lives, refers to the *Karma* in Hindu and Buddhist religious beliefs.
Karmarong	The true owners of the mountain, *Lama* people who prefer them to be called *Karma*rong.
Khas	A group/community of people from Aryan race who follow Hindu religious beliefs.
Khat khatai Sutka	Repeated pregnancies (births)
Khudamai/Khudabhitrai	While s/he was in baby cut, meaning that s/he is a very young newborn infant.
Khukuri	A traditional knife
Lama	A faith healer in *Lama* community; it also refers to a group /community of ethnic group who following Buddhist religious beliefs.
Lekhanta	Destiny, what was written
Maiti Dewata	The God of the parents family
Muiya/Muiyalagne	Influence of dead spirit, hungry spirit
Nwaran	The naming ceremony of a baby
Pakhala/Pakahalajane	Premature births, referred as of low concern like *Pakhala*, taken simply as a diarrhoeal condition
Patuka	A long piece of cloth used by women as a waist belt
Poili Dewata	The God of in-laws' or husband's family
Punya, Dharma	A spiritual/religious act, a benevolent act that is considered to liberate one, that is considered as per God's wish.
Raikosa	A *Lama* term to *Gotha*
Shraddha	Annual ritual after death of one's father/mother in Hindu belief
Sutka	Births
Talo	A piece of a cloth, usually torn from an old cloth such as a Woman's Sari or her cloth belt tied around her waist *(Patuka)*
Tuhinjhadne	Abortions
Kaitha/Kaithalagne	Labour pain

Tata	Tablet (medicines)
Sudeni	Traditional Birth Attendant
Paran	Cry (of baby at birth), life
Gotha Pasne	A belief which indicates that an adolescent girl is ready to marry
Deuda	Local folk singing and dancing
Bhagi Bibaha	A marriage system in which adolescent boy and girl briefly meet and like each other, the girl goes to live in boy's house and they are recognised as couple. They may or may not have formal cultural marriage ceremony.
Tike Bibaha	A marriage system in which bride's and bridegroom's parents have a consensus (like a contract) usually when a girl reaches seven years-old.
Purushatwa/Pitritwa	A perception of male identity which is believed to be tested by becoming a father
Matritwa/Naritwa	A perception of female identity which is believed to be tested by becoming a mother
Aputo/e	Couple without a child, used as a stigma to let a couple feel down
Kharanipani	Water mixed with ash (believed to traditionally abort a baby)
Umm Gaa	A newborn's cry
Sisiko	Looking filthy, referred to the vernix on the baby's skin
Ulto	Breech presentation during childbirth

Appendix 7: Initial Coding Framework

Parent Nodes	*Child Nodes*	*Sub Nodes*
		Availability
		Accessibility
	• *Access*	Affordability
		Appropriateness
		Acceptability
		Training and supervision
		Retention and turnover
HEALTH CARE DELIVERY	• *Human Resource*	Staff's personal & family issues
		Support staff
		Trust and relationships
		Policy, planning and management
		Recording and reporting
		Monitoring
	• *Health System Issues*	Referral and support system
		Accountability
		Resource allocation
		Private vs public

Equipment, supplies

Work environment

Corruption

- *Care seeking and receiving*

Care at family

Traditional care

Care from health institutions

Newborn care (boys vs girls)

- *Cultural norms, values and beliefs*

Why babies become sick & die (beliefs & perceptions)

Attitudes to health care

Child marriage

SOCIO-CULTURE AND BEHAVIOUR

Housing

Safety

- *Living Condition*

Heating

Water and Sanitation

Daily work contexts

Sex preferences

Status of young women and new mums

- *Gender*

Women's role

Men's role

NUTRITION AND
MATERNAL FACTORS

- *Food*

- *Early motherhood*

- *Maternal health*

Maternal nutrition

Obstetric complication

Family planning and
unintended births

POLICY AND POLITICS

- *Policies and strategies (non-health)*

- *Leadership and Commitments*

District and Village
Development Committee

Central Government

NGOs

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